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Exploring the use of home adaptation and related information  
for people with dementia living in domestic dwellings

By

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A thesis submitted in partial fulfilment of the requirements for  
the degree of Doctor of Philosophy in Engineering

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# Table of Contents

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List of Figures.....	xiii
List of Tables .....	xv
Acknowledgements .....	xvii
Declaration and inclusion of material from a prior thesis .....	xviii
List of Abbreviations .....	xx
Abstract .....	xxi
1 Introduction .....	1
1.1 Introduction .....	2
1.1.1 Evidence Based Healthcare Design.....	2
1.1.2 Staying at Home.....	3
1.1.3 Dementia .....	3
1.1.4 Information provision in healthcare .....	4
1.1.5 Summary of key principles .....	5
1.1.6 Scope of thesis .....	5
1.2 Research aims and objectives.....	6
1.2.1 Research Aims.....	6
1.2.2 Research Objectives.....	6
1.2.3 Research Questions .....	6
2 Literature Review: Evidence-based design for health and aging at home.....	8
2.1 Introduction .....	9
2.2 Design for Healing .....	10
2.2.1 Colour and Lighting.....	11
2.2.2 Artwork.....	13

2.2.3	Control over the Environment .....	13
2.2.4	Noise .....	13
2.2.5	Private Rooms .....	14
2.2.6	Preventing falls.....	15
2.2.7	Concluding thoughts on design for healing.....	15
2.3	Ageing at Home .....	16
2.3.1	The Ecology of Ageing .....	16
2.3.2	Control over the home environment.....	17
2.3.3	Access .....	18
2.3.4	Place Attachment.....	19
2.3.5	Housing Satisfaction .....	19
2.3.6	Concluding thoughts on aging at home.....	19
2.4	Residential and supported care design .....	21
2.4.1	Privacy .....	22
2.4.2	Legible Rooms .....	22
2.4.3	Artwork.....	23
2.4.4	Outdoors .....	23
2.4.5	Concluding thoughts on design in residential and supportive care.....	24
2.5	Where PwD live .....	24
2.6	Home adaptation: Changing the home to meet changing needs.....	26
2.6.1	Types of Home adaptation .....	27
2.6.2	How home adaptation can influence the lives of PwD.....	27
2.6.2.1	General room design.....	31
2.6.2.2	Lighting .....	31
2.6.2.3	Sound and Temperature.....	36
2.6.2.4	Flooring.....	37
2.6.2.5	Wayfinding.....	37
2.6.2.6	Bathrooms .....	39
2.6.2.7	Stairs .....	40
2.6.2.8	Views.....	43
2.6.2.9	Outdoor .....	43

2.6.2.10	Stimuli .....	43
2.6.3	CONCLUDING THOUGHTS ON DESIGN FOR DEMENTIA .....	44
2.7	Achieving Home adaptation in domestic environments .....	44
2.7.1	The Implementation of Home adaptation.....	44
2.7.1.1	The influence of informal carers .....	48
2.7.2	Concluding thoughts on home adaptation Implementation .....	49
2.8	Financial considerations of Home adaptation .....	49
2.8.1	Reducing healthcare costs.....	50
2.8.2	Willingness to Pay .....	51
2.9	Sources of Information and Products.....	53
2.9.1	Products .....	56
2.9.2	Concluding thoughts on information and products for PwD .....	58
3	Review of Literature: Health Behaviour Change Models .....	59
3.1	Health Behaviour Change Models .....	60
3.1.1	Transtheoretical model of health behaviour change .....	60
3.1.1.1	Pre-contemplation .....	61
3.1.1.2	Contemplation.....	62
3.1.1.3	Preparation .....	63
3.1.1.4	Action.....	63
3.1.1.5	Maintenance .....	63
3.1.1.6	Augmented Transtheoretical Model .....	64
3.1.2	Health Belief Model .....	65
3.1.2.1	Individual perceptions.....	65
3.1.2.2	Modifying Factors.....	65
3.1.2.3	Likelihood of Action .....	67
3.1.3	The Theory of Reasoned Action.....	67
3.1.4	Home adaptation implementation framework.....	68
3.1.5	Concluding thoughts on Health Behaviour change models and Home adaptation implementation .....	69
3.2	Literature Review Conclusion .....	71

4	Methodology.....	72
4.1	Introduction .....	73
4.1.1	Research Underpinning .....	73
4.1.2	Research Paradigm .....	73
4.1.3	Research Structure .....	74
4.1.3.1	Validity .....	75
4.1.3.2	Reliability .....	76
4.1.3.3	Generalisability.....	76
4.1.3.4	Scope.....	76
4.1.4	Study 1: Home Adaptation .....	77
4.1.5	Study 2: Information sources .....	77
4.1.6	Study 3: Practitioner knowledge and advice .....	77
4.1.7	Characteristics of the sample.....	78
4.1.8	Ethical considerations for the use of PwD in research .....	79
4.1.8.1	Person centred research.....	79
4.1.8.2	Researcher Attributes .....	80
4.1.8.3	Communication .....	80
4.1.9	The importance of using PwD in research.....	84
4.1.10	Conclusion.....	84
5	The Use of Home Adaption by people living with Dementia .....	86
5.1	Introduction .....	87
5.1.1	Aims and Objectives .....	87
5.1.2	Methodology.....	87
5.1.2.1	Study type.....	87
5.1.2.2	Sampling .....	88
5.1.2.3	Recruitment.....	88
5.1.2.4	Bracketing.....	89
5.1.2.5	Reflexive diary .....	89
5.1.2.6	Objective ADL measures .....	90
5.1.2.7	Data collection.....	90

5.1.2.8	Data analysis.....	91
5.1.3	Ethical Considerations .....	92
5.1.3.1	Informed consent.....	92
5.1.3.2	Participant Confidentiality .....	93
5.1.3.3	Data Security .....	93
5.1.3.4	Lone working considerations.....	94
5.1.3.5	Timescale .....	94
5.1.3.6	Ethical Approval.....	94
5.2	Results.....	94
5.2.1	Study Participants .....	94
5.2.1.1	Types of Dwelling .....	96
5.2.2	Maintaining familiarity, coping with change .....	97
5.2.2.1	Changing abilities .....	98
5.2.2.2	Changing technology.....	98
5.2.2.3	Maintaining Familiarity .....	99
5.2.3	Having knowledge and finding knowledge.....	101
5.2.3.1	Lack of knowledge.....	101
5.2.3.2	Sources of Information .....	102
5.2.4	Meeting Challenges through home adaptation .....	104
5.2.4.1	Self-derived adaptations.....	104
5.2.4.2	Physical vs Cognitive problems.....	105
5.2.4.3	Scale of changes .....	105
5.2.4.4	Attitudes towards adaptations.....	106
5.2.5	Discussion.....	107
5.2.5.1	Limitations to the present study .....	111
5.3	Conclusions .....	114
5.3.1	Next Steps .....	115
6	Dementia Information Sources: Review of the Literature .....	116
6.1	Introduction .....	117
6.2	Problems with information provision.....	121

6.2.1	Passive and Active Information.....	121
6.2.2	Tacit versus Explicit knowledge.....	122
6.2.3	Quality and Accessibility.....	122
6.2.4	Relational versus Non-relational sources.....	123
6.2.5	Relationship between factors.....	124
6.2.6	The Internet.....	126
6.2.6.1	The influence of age on internet use.....	127
6.3	Information source preference and dementia.....	128
6.3.1	Topics of information.....	129
6.4	Concluding thoughts on sources of dementia information.....	129
7	Information source preferences and use among family and friends of those with dementia.....	131
7.1	Introduction.....	132
7.1.1.1	Research Questions.....	132
7.2	Methods.....	133
7.2.1	Recruitment.....	133
7.2.1.1	Inclusion Criteria.....	133
7.2.1.2	Exclusion Criteria.....	133
7.2.2	Study Type.....	134
7.2.3	Piloting.....	135
7.2.4	Data Analysis.....	135
7.2.5	Ethical Consideration.....	136
7.3	Results.....	137
7.3.1	Characteristics of the sample.....	137
7.3.2	Where do PwD and their family and friends currently access information regarding dementia?.....	141
7.3.2.1	The internet.....	141
7.3.2.2	The effects of age.....	141
7.3.2.3	Relational Information Sources.....	144



7.3.3	How accessible, trustworthy, credible and comprehensible do PwD and their carers consider the available sources of information? .....	151
7.3.3.1	Trustworthiness.....	151
7.3.3.2	Accessibility .....	152
7.3.3.3	Comprehension .....	154
7.3.3.4	Quality.....	154
7.3.4	How would PwD and their family and friends like to receive information? 155	
7.3.4.1	Education level .....	158
7.4	Discussion .....	158
7.4.1	Internet.....	161
7.4.2	Media complementarity.....	162
7.4.3	Socioeconomic aspects .....	164
7.4.4	Tacit, explicit or embedded knowledge.....	164
7.4.5	Individualised information .....	165
7.4.6	Limitations.....	166
7.5	Conclusion.....	167
8	Home adaptation for dementia: Information provision by practitioners in the UK.....	169
8.1	Introduction .....	170
8.1.1	General Practitioner Knowledge.....	172
8.1.2	Occupational Therapists .....	173
8.1.3	Support Groups.....	174
8.1.4	Information Seeking and learning for practitioners.....	175
8.1.5	Summary .....	175
8.2	Aims.....	176
8.2.1	Research Questions .....	176
8.3	Methods.....	176
8.3.1	Recruitment .....	176
8.3.1.1	Participants.....	177

8.3.2	Study Type.....	177
8.3.2.1	Questionnaire development.....	177
8.3.2.2	Questionnaire pilot .....	178
8.3.3	Data collection .....	179
8.3.4	Data analysis .....	180
8.3.4.1	Closed questions .....	180
8.3.4.2	Open questions .....	180
8.3.4.3	Vignettes.....	180
8.4	Results.....	181
8.4.1	Characteristics of the sample.....	181
8.4.2	How home adaptation knowledge has been obtained.....	183
8.4.3	How home adaptation knowledge is provided .....	187
8.4.3.1	The types of recommendations and equipment provided by service 188	
8.4.4	Vignettes .....	190
8.4.4.1	Vignette Summary.....	191
8.5	Discussion .....	192
8.5.1	Where do individuals offering face-to-face support to PwD and their carers access knowledge and / or receive training about home adaptation for dementia?.....	193
8.5.2	Which services and /or practitioner roles currently offer advice about modifying the home environment to PwD and their carers? .....	194
8.5.3	What is the extent of, and method of delivery for, home adaptation advice? 195	
8.5.4	Further findings.....	196
8.5.5	Limitations to the current study .....	197
8.6	Conclusion.....	197
9	General Discussion .....	199
9.1	Introduction .....	200
9.2	Summary of Research findings .....	200

9.2.1	Home adaptation study (Chapter 5) .....	200
9.2.2	Information sources study (Chapter 7).....	200
9.2.3	Practitioner home adaptation knowledge study (Chapter 8).....	201
9.3	Implications.....	202
9.3.1	Behaviour change models .....	203
9.3.1.1	Actuation .....	204
9.3.1.2	Awareness .....	205
9.3.1.3	Acceptance .....	205
9.3.1.4	Access .....	208
9.3.1.5	Review.....	209
9.3.1.6	Alternative route .....	210
9.3.2	Optimal Home Adaptation Phase .....	210
9.4	Recommendations for increasing the uptake of home adaptation for dementia .....	211
9.4.1	Recommendations for PwD and their carers .....	212
9.4.1.1	Proactive home adaptation can provide long term support .....	212
9.4.1.2	Consider how changes and new technology affect dementia symptoms	212
9.4.1.3	Use a broad range of sources to feel well informed about dementia	213
9.4.1.4	Consider making changes to your home before issues arise.....	213
9.4.2	Recommendations for practitioners and service leads .....	213
9.4.2.1	Earlier provision of home adaptation information.....	213
9.4.2.2	Benefits of early adaptation .....	214
9.4.2.3	Improved training.....	214
9.4.2.4	Service change to focus on pre-crisis intervention .....	214
9.4.2.5	Providing free of charge, evidence based information.....	214
9.4.2.6	Provision of individualised information .....	215
9.4.3	Recommendations for designers and industry .....	215
9.4.3.1	Mainstream dementia information and design.....	215
9.4.3.2	Retail opportunities lie within dementia design.....	216

9.4.4	Recommendation Priorities.....	216
9.5	National and International dementia trends .....	217
9.6	Limitations .....	219
9.6.1	Recruitment .....	219
9.6.2	Using PwD in research .....	220
9.6.3	Sample Size .....	221
9.6.4	Structure of Surveys .....	221
9.7	Future Research.....	221
10	Conclusions .....	225
10.1	Conclusions .....	226
10.1.1	Research Objective One: To discover the lived experiences and perception of home adaptation by PwD and their carers .....	226
10.1.2	Research Objective Two: To investigate the information seeking preferences and behaviours of PwD and their carers.....	227
10.1.3	Research Objective three: To investigate practitioner knowledge and practise in relation to home adaptation advice .....	228
10.1.4	Final Remarks .....	229
11	References .....	230
12	Appendices.....	257
12.1	Appendix A: PIL Home Adaptation Study .....	258
12.2	Appendix B: Consent form Home Adaptation Study .....	262
12.3	Appendix C: Bracketing framework for Home adaptation study .....	263
12.4	Appendix D: Interview schedule for Home Adaptation Study .....	264
12.5	Appendix E: Information Sources questionnaire derivations.....	267
12.6	Appendix F: Information sources postal questionnaire including PIL and consent form .....	271
12.7	Appendix G: NICE dementia publications and their relevance to home adaptation .....	304

12.8	Appendix H: Practitioner study questionnaire including vignette scenarios and derivations .....	306
12.9	Appendix I: Recommendations leaflet .....	309

## List of Figures

---

Figure 1. Structure of Literature review .....	9
Figure 2. Design consideration for health environments .....	11
Figure 3 Evidence based design aspects for dementia .....	28
Figure 4. Transtheoretical Model of Health Behaviour Change.....	61
Figure 5. Augmented Transtheoretical model of health behaviour change .....	64
Figure 6. Health Belief Model .....	66
Figure 7. Theory of Reasoned Action.....	67
Figure 8. Factors of influence over home adaptation implementation.....	68
Figure 9. Implementation Framework for home adaptation .....	70
Figure 10. Research methods structure .....	75
Figure 11. Summary of interview schedule themes .....	91
Figure 12. Themes drawn from the data.....	97
Figure 13. Explanatory framework of home adaptation following a dementia diagnosis .....	113
Figure 14. Comprehensive Model of Information Seeking.....	120
Figure 15. Interplay between Information source characteristics.....	125
Figure 16. Highest level of education achieved by respondents .....	139
Figure 17. Length of time since dementia diagnosis .....	140
Figure 18. Sources actively searched for information .....	142
Figure 19. Where respondents use the internet .....	143
Figure 20. Types of website used for dementia information .....	143

Figure 21. Likelihood of using the internet to find dementia information with reasons given .....	146
Figure 22. From which sources have respondents received passive information about dementia .....	150
Figure 23. Perceived trustworthiness .....	152
Figure 24. Perceived accessibility .....	153
Figure 25. Perceived Comprehension.....	154
Figure 26. Perceived quality of passive information provided by relational sources	155
Figure 27. Roles of practitioner participants.....	182
Figure 28. Area of work .....	182
Figure 29. Length of time in a role giving advice to PwD or their carers.....	183
Figure 30. Sources of passive information about modifying the physical environment in dementia .....	184
Figure 31. Sources of information used for active searching.....	184
Figure 32. Methods of delivery of home adaptation for dementia advice by practitioner .....	188
Figure 33. How likely are clients to carry out home adaptation recommendations? .....	189
Figure 34. The Four As of influence in home adaptation implementation .....	204
Figure 35 Home adaptation in dementia framework .....	207

## List of Tables

---

Table 1	Summary of evidence based design for dementia in domestic dwellings ....	30
Table 2.	Changes in Visual ability in ageing and dementia .....	35
Table 3.	Optimal Staircase design for falls prevention .....	42
Table 4.	Common sources of home adaptation literature .....	55
Table 5	Topics covered by home adaptation literature.....	57
Table 6.	Considerations for the use of PwD in qualitative research .....	83
Table 7.	Participants without dementia .....	95
Table 8.	Participants with dementia .....	96
Table 9.	Types of housing occupied by participants .....	97
Table 10.	Where do you reside? .....	137
Table 11.	What is your gender? .....	138
Table 12.	How would you describe your ethnicity?.....	138
Table 13.	Relationship of respondent to PwD.....	139
Table 14.	Type of dementia diagnosed .....	140
Table 15.	Number of respondents using relational sources .....	145
Table 16.	Ranked placings for where respondents would look first for information about a range of topics.....	148
Table 17.	Reasons given for not considering a support group.....	149
Table 18.	Have you ever acted upon passive information? .....	151
Table 19.	Spearman's Rho correlation co-efficient between accessibility and perception of information sources.....	153



Table 20. Correlations between Likert scores for how close to ideal is the current sources of information and experiences of information searching.....	156
Table 21. Relational and Non-relational sources identified as ideal by participants	157
Table 22. Vignette scenarios and the symptoms they address.....	178
Table 23. Participants by age group .....	183
Table 24. Percentage changing practice after gaining knowledge about the home environment and dementia .....	186
Table 25. How practitioners changed their practice after finding information about the physical environment and dementia .....	186
Table 26. Level of Knowledge and feelings of knowledge of home adaptation in dementia by practitioners.....	187
Table 27. Types of adaptation described for vignettes .....	190
Table 28. Percentage of practitioners giving advice over all scenarios by service type .....	192
Table 29. Referrals by vignette number .....	192
Table 31. Summary of recommendations and their derivations .....	212

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## **Declaration and inclusion of material from a prior thesis**

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The author declares that the work contained within this thesis is her own work and has not been used previously.

The work has not previously been submitted for examination at any other University or institution.

**Aspects of the work presented in this thesis were published in the following public places:**

Allen, F., Cain, R. and Meyer, C. (2018) 'Seeking relational information in the digital age: A study into information source preferences among family and friends of those with dementia '. Accepted Manuscript: Dementia. Sage publications

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Allen, F., Cain, R. and Meyer, C. (2017) 'How people with dementia and their carers adapt their homes. A qualitative study', Dementia. SAGE Publications, p. 1471301217712294. doi: 10.1177/1471301217712294.

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Allen, F. (2017) 'What is dementia and why are we bothered?' [Blog] WMG. Shaping the future. Available at: <http://www.wmgshapingthefuture.co.uk/what-is-dementia/>

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## List of Abbreviations

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PwD	Person/People with dementia
OT	Occupational Therapist
NHS	National Health Service
JDR	Join Dementia Research
GP	General Practitioner
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
HINTS	Health Information National Trends Survey
ADL	Activities of Daily Living
PIL	Participant Information Leaflet

## Abstract

---

Dementia is an umbrella term used to describe several progressive diseases, characterised by symptoms of cognitive dysfunction and communication difficulties which cause difficulties with day to day functioning and frequently led to health and social care crises. The preferred place of habitation for People with Dementia (PwD) is to remain in their own home throughout their life which offers familiar surroundings and a sense of control.

Evidence-based healthcare design has been shown to be beneficial in the homes of PwD by reducing challenging dementia symptoms and behaviours. These concepts include the adaptation the home via changing colour, lighting, sound and temperature. Advice detailing how these concepts can be used by PwD and their carers at home is available from a number of different sources. However, it remains unclear how home adaptation information is accessed and utilised and what the barriers to home adaptation are.

The project consisted of three studies: Firstly, a qualitative exploratory study looking at the use of home adaptation by PwD and their carers in their own home. The second study investigated how comprehensible and accessible people find different information sources and how participants would prefer to receive information about dementia. The third study attempted to identify what home adaptation information is provided by health, social care and charity practitioners and how professionals feel about their own level of home adaptation for dementia knowledge.

The overall results led to the production of recommendations which have the potential to improve the uptake of home adaptation for dementia in domestic dwellings. These include providing individualised home adaptation information provided closer to diagnosis. This would encourage dementia specific adaptations to be completed within the Optimal Home Adaptation Phase, described as the time between diagnosis and the time where deterioration makes familiarity the driving force of the home environment.

# 1 Introduction

## 1.1 Introduction

---

This chapter introduces the themes of Evidence Based Healthcare Design, staying at home into old age, information seeking and dementia. It then brings together how they relate to the aims of the research. Initially it introduces the concept of healthcare design before describing information provision within healthcare. These aspects led us to consider healthcare design within the domestic dwelling with specific reference to dementia and how this is influenced by the provision of evidence-based information. Finally, the aims of the research are discussed.

### 1.1.1 Evidence Based Healthcare Design

The term 'Evidence-based design' describes the creation of healthcare environments which are supported and informed by research (Huisman *et al.*, 2012). The field of Evidence-based design has been a feature of healthcare for centuries. As far back as the nineteenth century both the Poor Law Board and Florence Nightingale provided recommendations on the amount of space required to nurse the sick (Hignett and Lu, 2010). The relationships between the built, physical environment and health and wellbeing have been widely studied in a number of different fields including human geography, physiological anthropology, ergonomics and health sciences. This has shifted healthcare design away from that of purely functional space in which to deliver healthcare, towards more holistic environments which take into account the effects of the physical environment on both physical and psychological healing and well-being of patients.

Recently there has been a revolution in healthcare which has moved treatment and care away from the inpatient hospital setting, with more emphasis now being put on keeping people at home for longer and preventing hospital admission. Hospital admissions increase the risk of infection, increase costs and are detrimental for many long term conditions (Department of Health, 2001). Medical procedures that were once the preserve only of the hospital or clinic now take place in the home for



example: recovery from acute illness, rehabilitation following elective surgery, blood transfusions and nursing care.

### 1.1.2 Staying at Home

Financial and medical drivers are important reasons for healthcare taking a larger community role, however perhaps the most significant motivation is that it is the preferred option for the majority of people (Lloyd, 2015). This allows for a higher level of perceived choice and privacy for people using health services. However whilst hospital and residential care design is influenced by architects, designers, healthcare staff and service users, domestic dwellings are a very personal and private space influenced predominately by the people who inhabit them.

In the UK there is an aging population with one in five people being over 65 (Office for National Statistics, 2012b). This is set to rise to one in four by 2050. The over 80 age group is growing the fastest, it is estimated that there will be six million people in this demographic by 2030 (Cracknell, 2010). Remaining in their own home and 'Aging in place' is the preferred outcome for the majority of older people (Sixsmith *et al.*, 2004; Lansley *et al.*, 2005; Hwang *et al.*, 2011). As they get older, people who choose to remain in their home require support of health and social care to allow them to stay at home even through periods of acute ill health and managing long term conditions. 58% of people over 60 have at least one long term condition and 25% have two or more (Department of Health, 2005).

### 1.1.3 Dementia

In the UK, one in fourteen people over 65 and one in six people over the age of 80 will be diagnosed with dementia (Alzheimer's Society, 2014). Dementia is an umbrella term for a range of symptoms caused by degeneration of areas of the brain. This damage becomes progressively more pronounced and causes cognitive impairment, reduced communication, reasoning and loss of functional capacity. There are several different types of dementia, the four most common being:

- Alzheimer's disease: The most common form of dementia. Caused through protein plaques forming on nerves within the brain leading to cell death. Characterised by a loss of short term memory but also leads to deficits in thinking, reasoning, perception and communication.
- Vascular Dementia: The second most common type of dementia. Caused by infarcts in the brain which present as a series of small strokes. Deterioration occurs in a series of steps as more infarcts occur. Symptoms include problems with visuospatial awareness, language, memory and concentration.
- Dementia involving Lewy bodies: Deposits of protein on nerve fibres cause death of nerve fibres and cells within the brain. Symptoms include, loss of movement, sleep disturbances, hallucinations and problems with attention.
- Frontotemporal dementia (also called Pick's disease): Caused by atrophy of the frontal and temporal lobes of the brain. More common in early onset dementia (under 65 years) Symptoms include behavioural changes, losing fluency and comprehension of speech. Memory and cognition are less affected during the early stages (The Alzheimer's Society, 2016)

There are many rarer and atypical forms of dementia which manifest a range of these impairments, however, typically the main symptom is loss of short term memory and cognition. All of these symptoms of dementia can have wide ranging effects on how people interact and are assisted or restricted by their environment.

#### **1.1.4 Information provision in healthcare**

Historically the most prominent and trusted source of information relating to healthcare was from healthcare professionals such as doctors, nurses and allied health professionals (Johnson and Case, 2012). Recently more modern and accessible methods of finding health information have become available, now there is an increasing reliance on digital sources of information, which are more accessible and therefore quick to use (Kort S.M. and van Hoof, 2014). Finding information about health can be used as a coping mechanism for those coming to terms with the diagnosis of a long term condition, either for themselves or as someone for whom

they care (Edelman *et al.*, 2006). Therefore information seeking is both important because it offers practical advice and emotional support for individuals living with a medical condition.

### **1.1.5 Summary of key principles**

Therefore, evidence suggests that finding ways of managing people at home through ill health and aging has benefits for health and social care, and it is the popular choice for many people. Dementia is a significant cause of ill health and a move from home living to residential care or hospital admission. Good environmental design has been shown to have a positive effect on health outcomes in hospitals but the question is how can this be migrated to domestic homes in the real world?

### **1.1.6 Scope of thesis**

The focus of the research within this thesis concerns PwD who live in domestic dwellings and the impact of evidence-based design recommendations on their lives. Therefore, end of life care, although a feature of dementia due to its progressive and terminal nature is not discussed here. This is because end of life care represents a speciality in its own right, where there is a large increase in the input from health and social services. Additionally, as a symptom of dementia is a loss of mobility in the end stages, housing modification becomes less influential on the experiences of PwD and their carers at this point.

The term 'Home adaptation' here refers to physical changes made to the home environment specifically to improve or sustain functional abilities and symptoms for PwD. This includes the addition of living aid equipment and decorative changes. It stops short of including digital assistive technology which involves issues relating to the acceptance and usability of technology by PwD and their carers.

## 1.2 Research aims and objectives

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### 1.2.1 Research Aims

This research sets out to review the current evidence for how the home environment can be both adapted and better designed to meet the needs of people with dementia. It then aims to investigate how this evidence is being used by people with dementia. It aims to increase knowledge about how people with long term illness feel their homes and then to look at where individuals look for information about dementia and the types of advice about home adaptations that is provided by practitioners. This leads to the overarching aim of how information can be better disseminated to this population in order to increase the use of evidence-based design in domestic dwellings.

### 1.2.2 Research Objectives

1. To discover the lived experiences for PwD and their carers in relation to:
  - Home adaptation
  - Information seeking behaviour.
1. To investigate the information seeking preferences and behaviours of PwD and their carers and how this may change through the disease process and with different demographic groups.
2. To use the knowledge from Objectives 1 and 2 to recommend and develop appropriate ways of providing home adaptation education.

### 1.2.3 Research Questions

Advice on adapting the home environment to promote independence in dementia care is available to all from a variety of patient support groups and internet sources such as the Dementia Services Development Centre and the Alzheimer's society as well as from healthcare professionals such as OTs and specialist nursing teams. Little is known, however, about how PwD and their carers access and use this advice.

In this thesis the following research questions are considered:

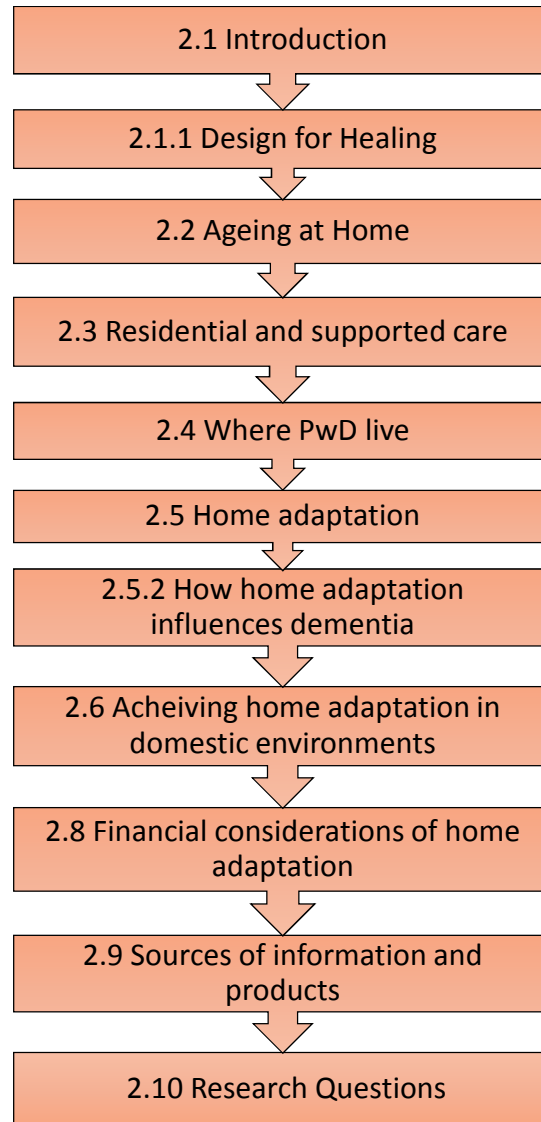
- How are PwD and their carers adapting their homes for independent living?
  - Where do they access advice from?
  - When are adaptations made and by whom?
  - How effective do carers and PwD perceive the adaptations made?
- What are the barriers to adaptation and how can these be overcome?

## 2 Literature Review: Evidence-based design for health and aging at home

## 2.1 Introduction

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This chapter provides a background into the current body of evidence surrounding the research areas of the thesis (Figure 1) to arrive at the research questions.



*Figure 1. Structure of Literature review*

The review begins with an overview of evidence-based design for healthcare before moving on to examine aspects relating to the challenges of aging within the home environment and the impact of dementia. The main body of the chapter focusses on how the impairments due to aging and dementia can be overcome through home adaptation and design for dementia respectively. The final sections look at the

financial implications of these solutions and how information regarding home adaptation is distributed and utilised.

The challenges are split into those created by the normal aging process and those created through dementia, however it is unlikely that these will present as mutually exclusive. As previously discussed, dementia is predominantly a disease of old age which means challenges are likely to arise from multiple morbidities, therefore both strands of dementia and aging are discussed here.

## 2.2 Design for Healing

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In his seminal paper, Ulrich (1984) found that different views through ward windows led to differences in analgesic use, anxiety and delirium for patients recovering from surgery. His retrospective study looked at data from a gastrointestinal ward, specifically from gall bladder surgery over a nine year period. Due to the design of the ward, a patient's room either overlooked a group of trees or a plain brick wall. Patients who saw trees through their room window had significantly shorter lengths of hospital stay and used both less and weaker forms of analgesia than the patients who looked out on the wall (Ulrich, 1984). It has been suggested that the ways that hospital environments can be designed to reduce stress responses are by allowing control, social interaction and distraction (Ulrich, 1991, 1992; Andrade and Devlin, 2015)

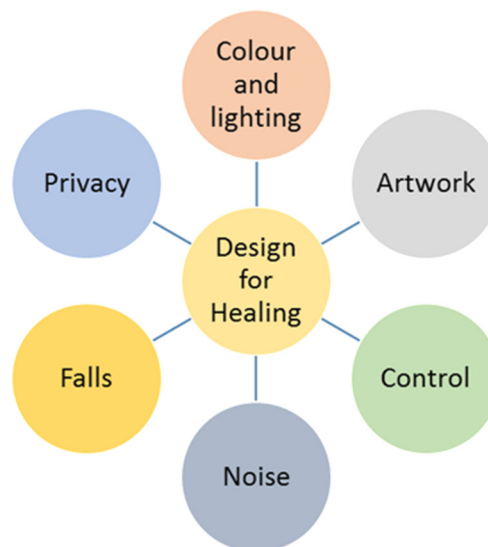
Health facility design affects all who use the facilities: patients, relatives, staff and visitors (Cesario, 2009). The design of the physical environment can be split into three areas: architecture, interior design and ambient features (Harris *et al.*, 2002). Much of the research appraised here has concentrated on a mix of these design areas and their effect on a variety of patient outcomes and health specialities, predominantly within inpatient settings.

The interior design of hospitals was investigated by Caspari *et al* (2011). They interviewed professionals from the field of aesthetics who also had experience of being patients in hospital. The semi-structured interviews concentrated on how the participants felt about the aesthetics of their surroundings during their inpatient



experience. The comments made by designers and architects offer a good level of insight into how patients are affected by the aesthetics of the ward. The main desire of the patients interviewed was for a homelike environment especially within bedrooms (Caspari, Eriksson and Nåden, 2011). However, although Improving the homeliness of healthcare environments is often cited as desirable it is difficult to measure, with different researchers linking it to either room size, soft furnishings or ward culture (Dijkstra, Pieterse and Pruyn, 2006; Caspari, Eriksson and Nåden, 2011; Marquardt, Bueter and Motzek, 2014; Andrade and Devlin, 2015).

As shown in Figure 2 there are a number of design considerations that have been discussed in the literature. This chapter will now look at these in more detail.



*Figure 2. Design consideration for health environments*

### **2.2.1 Colour and Lighting**

Colour is widely used to assist with way-finding in large hospitals but provides the most beneficial responses when considered in relation to lighting. Colour and contrast require good levels of lighting to assist with the definition of detail (Dalke *et al.*, 2006) but glare, especially on floors, can cause a trip hazard for visually impaired and older people (Pocklington, McCabe and Dawson, 2014).

Access to natural light has been shown to reduce depression and feelings of anxiety (Henriksen *et al.*, 2007). Acute psychiatric disorders require bright lighting levels at different times of day to gain the most benefit. Morning sunlight has been shown to reduce symptoms in Bipolar disorder and dementia (Dijkstra, Pieterse and Pruyn, 2006). However, it remains unclear whether natural light has a superior effect on health than similar levels of electric lighting. The differences may come in the production of vitamin D and the wavelengths of light produced. Vitamin D has been linked to resistance to depression, schizophrenia and autoimmune disease and is produced when skin is exposed to sunlight (Beute and de Kort, 2014). Wavelengths of light can be reproduced by artificial lights to mediate the absence of daylight, for example the use of bright light therapy in seasonal affective disorder and dementia (Beute and de Kort, 2014)

Windows provide increased natural light and also create a connection with the outside environment and nature. There is a long tradition in western culture that links the natural environment with physical and mental wellbeing. Flowers and greenery have been shown to improve well-being (Caspari, Eriksson and Nåden, 2011). In a small study involving students and their perceptions of stress in a hospital room both with and without indoor plants, it was found that the presence of indoor plants reduces stress. However, this study by Dijkstra *et al* (2008) however relied on healthy students imagining the stress of a hospital admission and therefore may not be transferrable to real hospital scenarios, they also discuss the impact of plants on infection control and their potential to introduce bacteria through the soil (Dijkstra, Pieterse and Pruyn, 2008). Viewing nature has been shown to have positive effects on mood and stress which has been linked to reduced disease severity and negative emotions (Ulrich, 1991; Beute and de Kort, 2014; Andrade and Devlin, 2015). Views of nature have a positive effect if either viewed directly through a window or indirectly on artwork or pictures (Caspari, Eriksson and Nåden, 2011)

### 2.2.2 Artwork

The provision of artwork in hospital environments is thought to act as a positive distraction. In a review of a novel scheme to allow long term patients on a cancer care ward to choose their own artwork, it was found that patients found comfort in the ability to create a more homely environment and that the pictures facilitated communication and socialisation with visitors and nursing staff (Suter and Baylin, 2007) . Although the research was a case study of a small scale project and only covered one cancer care ward and had no objective markers, it offers insight into the potential benefit of visual art for patients (Suter and Baylin, 2007). Views and pictures of nature have a positive effect on negative emotions and hold attention for longer and these benefits may increase with increased exposure (Ulrich, 1991; Caspari, Eriksson and Nåden, 2011). Abstract art, however, has been shown to have negative effects in the healthcare setting (Daykin *et al.*, 2008; Huisman *et al.*, 2012).

### 2.2.3 Control over the Environment

The study by Suter and Baylin (2007) outlined above also highlighted the improvements to well-being that can be achieved through control over the environment. Patients often lack autonomy in hospital which leads to feelings of helplessness and decreased motivation (Gesler *et al.*, 2004). This lack of control can be caused through the nature of their illness, the culture of the ward and having to rely on staff for aspects of care for which they are normally independent (Andrade and Devlin, 2015). Designing healthcare spaces which allow for an element of control can mediate the stress felt on admission (Gesler *et al.*, 2004). Examples of this include control of heating, bed position, light and social interaction (Huisman *et al.*, 2012).

### 2.2.4 Noise

Differing aspects of sound have an impact on healthcare environments. Noise or unwanted sound has been shown to raise blood pressure, increase the use of analgesics and reduce the quality of sleep for ward patients (Reiling, 2006; Joseph and Ulrich, 2007). Different types of noise have different effects, for example a long

reverberation rate combined with a noisy environment can create difficulty listening to speech. Design can mediate the effects of noise and sound by the addition of sound reducing factors such as sound absorbing materials, reducing the number of noise creating sources and creating more single patient rooms (Dijkstra, Pieterse and Pruyn, 2006)

### **2.2.5 Private Rooms**

The provision of single room accommodation is largely seen as a positive feature allowing for privacy and reducing noise pollution for patients. However, it has also been shown that patients in private rooms were more than twice as likely to suffer an adverse event and feel social isolation compared with patients in a traditional ward setting (Hignett and Lu, 2010). However Van de Glind, de Roode, & Goossensen (2007) found little evidence for the effects of single rooms on patient safety. They found that patients in single rooms spend longer talking to consultants during ward rounds and were able to ask more questions than patients in a four bedded bay. One of the most important findings was that patients who stay in single rooms are more satisfied with the level of their care than their counterparts in the multi-bedded bay (van de Glind, de Roode and Goossensen, 2007).

Good healthcare design needs to incorporate aspects relating to both aesthetics and health and safety. Carpet for example has been shown to have a beneficial effect on noise levels and homely appearance but is contraindicated in wards due to difficulty cleaning in order to prevent the spread of infection (Nanda, Malone and Joseph, 2012). Design benefits for patients may have negative effects on staff. For example, wards involving single patient bedrooms have been found to increase the risk of staff burnout because of the increased difficulty in observing patients and an increase in lone working whilst on the ward (Tyson, Lambert and Beattie, 2002). This study used observation, questionnaires and interviews with staff working in acute psychiatric care. The results showed that staff overwhelmingly thought the new ward design was better for patients but that it increased stress and burnout for staff.

### 2.2.6 Preventing falls

The importance of risk management in modern healthcare means that much research has been conducted into the prevention of patient falls in healthcare settings. (Lee, Mills and Watts, (2012) found that the physical environment was the most common root cause for falls in mental health units. Slippery floors, furniture, narrow doorways, insufficient lighting and lack of grab rails can all impact negatively on the incidence of falls (Cesario, 2009; Lee, Mills and Watts, 2012). In a retrospective review of Swedish records Kallstrand-Ericson and Hildingh found that falls in elderly inpatients were more common at night when lighting was dimmed. All of the fallers documented had a degree of visual impairment. Their research supports the argument for contrasting colours and lighting in hospitals (Källstrand-Ericson and Hildingh, 2009). A larger study of English and Welsh data from the National Patient Safety Agency (NPSA) found in contrast that the peak time for falls was in the late morning when patients were more active (Healey *et al.*, 2008). It has been found that twelve percent of inpatient falls occur when trying to stand from sitting, therefore furniture of the correct height could reduce the incidence of falls (Scanlan, Wheatley and McIntosh, 2012).

### 2.2.7 Concluding thoughts on design for healing

Whilst the breadth of Evidence-based design in health is growing, much of the research relies on small scale studies and case studies with the focus being on inpatient settings such as hospitals. On the whole, studies were attempting to measure subjective variables such as comfort and mood. There remains a lack of knowledge and empirical evidence regarding how the evidence can be transferred or modified for other healthcare environments for example domestic and clinic settings.

The NHS “Five year Forward View” launched in October 2014 reemphasised the commitment to treat people in their own home and manage their conditions more effectively in the community (NHS England, 2014). Therefore with the transformation of the home into a healthcare environment it is important to understand how the physical environment of domestic dwellings affects the way in which individuals interact with healthcare services administered at home.

Indeed the domestic environment already contains many of the aspects which are surmised by previous evidence to improve well-being in health environments such as private space, control and a homely environment. In order to begin to understand the relationship between people at home and healthcare, it is necessary to begin to understand how people feel about their homes and how this changes due to changing health. It is also beneficial to look at how groups of patients already modify their homes in light of both a diagnosis and evidence from research.

## 2.3 Ageing at Home

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### 2.3.1 The Ecology of Ageing

The Ecology of Aging proposed by Nahemow & Lawton, (1973) describes the interaction with the environment as people age. The concept contains different co-existing processes:

- **Press-Competence model:** Environmental Press describes aspects of the environment which have a motivating effect on the individual (either consciously or unconsciously). This model hypothesises that either a decrease in competence or an increase in the amount of environmental press leads to a decrease in function.
- **Environmental Docility Hypothesis:** The less able an individual becomes, the greater the limiting influence of the environment becomes (Crews, 2005)
- **Person-environment (P-E) fit:** Level of congruence between the needs of the individual and the ability of the environment to meet these needs (Nahemow and Lawton, 1973)

Maladaptive behaviour such as stress and impairment are caused through changes in environmental press and environmental fit. 'Aging in Place' is one way that individuals maintain consistency in the environment. However, the aging process and ill health create continually changing levels of competence. Modification of the environment aimed at decreasing Environmental Press can mitigate for changes in personal competence (Nahemow and Lawton, 1973; Lawton, 1985; Moore *et al.*, 2003).

Person-Environment (P-E) fit can be used as an indicator of safety in the home. Iwarsson et al. (2009) reviewed data from the ENABLE-AGE study (Sixsmith *et al.*, 2004) and found that P-E Fit provided a more accurate and tailored prediction of falls than an assessment of environmental hazards alone. However the reporting of falls was subjective (H.-W. Wahl *et al.*, 2009). Participants were asked about recent falls but no time frame was provided and this relied on the memory of the participants. Although further research into this area is needed to form a more conclusive picture, the results add to the evidence that an individualised assessment of the home environment is more beneficial than generalised information.

Reduced life space, which is the ability to move purposefully around the home, is linked to frailty and an inability to meet environmental challenges such as steps and stairs (Cohen-Mansfield, Shmotkin and Hazan, 2012). This demonstrates the effect of environmental stimuli increasing with age. Iwarsson *et al.*, (2007) argue that although the link between the home environment and well-being appears plausible there is a lack of unbiased evidence.

### 2.3.2 Control over the home environment

The ability to have control over the home environment allows people to make choices and is therefore seen as a positive attribute. Locus of Control theory proposed by Rotter (1966) states that control beliefs can be separated into two types:

- **Internal:** A person with higher levels of internal control perceives housing related decisions are linked to their own behaviour.
- **External:** Increased feelings of external control leads to housing related experiences being perceived to be reliant on luck, chance or others (Rotter, 1966; Oswald *et al.*, 2006).

Wahl et al. (2009) found that when older people feel that housing related issues are out of their control they have a lower level of well-being. The Enable-Age study (2004) was an important investigation of the influences of the home in healthy aging. A qualitative interview study was completed across five European countries (Sweden,

Latvia, UK, Germany and Hungary). The project consisted of three main parts, the first a review of housing policies, the second a longitudinal survey (n=1918) and the third involved interviews and case studies.

Analysis of the data gained formed the basis for a number of publications (Oswald *et al.*, 2006, 2007, Iwarsson *et al.*, 2007, 2009; Fänge and Ivanoff, 2009; H.-W. Wahl *et al.*, 2009; Hwang *et al.*, 2011). H.-W. Wahl, Schilling, Oswald, & Iwarsson, (2009) used data from the Swedish and German part of the project to examine the relationship between magnitude of accessibility problems and Housing- Related Control Beliefs. They found that the size of accessibility problems correlates positively to dependence for Activities of Daily Living (ADL) and depression and negatively to life satisfaction (H.-W. Wahl *et al.*, 2009). This is supported by other studies which show that older people who are housebound have significantly higher levels of depression than those who are ambulatory (Choi and McDougall, 2007; Cohen-Mansfield, Shmotkin and Hazan, 2010, 2012; Qiu Qiao *et al.*, 2010).

### **2.3.3 Access**

The ability to enter or exit the home impacts on how it is used by the occupants. In a separate study of ENABLE-AGE data it was found that it is the level of difficulty in access to property, rather than that the number of separate environmental barriers which increases in the home in old age (Iwarsson *et al.*, 2007). Pettersson, Löfqvist, & Malmgren Fänge, (2012) found that the most important outcome of housing adaption was providing the ability to spend time outdoors by improving access. The study concluded that behavioural responses to home and low external control beliefs were linked to independence. However it remains unclear what the causal relationship of these findings are, whether people who are physically independent due to internal factors such as strength, have greater place attachment and feel more in control of their surroundings or whether place attachment and a feeling of control over the environment motivate people to maintain their independence.



### **2.3.4 Place Attachment**

Place attachment is the emotional attachment placed on an environment. It includes feeling comfortable and familiar with surroundings and usually occurs after living somewhere for an extended period of time (Oswald *et al.*, 2011). Oswald *et al.* (2011) looked at factors affecting place attachment and life satisfaction on young-old (65-80) and old-old (over 80). They found that having a larger living space increased satisfaction in young-old but decreased it in the old-old group. The area of living space used significantly correlates to the amount of physical activity completed by older people (Cress, Orini and Kinsler, 2011). However when comparing community living and retirement community living residents, the retirement community group mobilised more outside in the grounds.

What the causal factors are in the changes to place attachment as older people age further are not fully revealed by the research by Cress, Orini and Kinsler, (2011; or Oswald *et al.*, (2011) and it is less clear how changes in place attachment affect the decisions made by individuals about their living environments.

### **2.3.5 Housing Satisfaction**

Housing satisfaction relates to how psychologically satisfied a person is with their home (Oswald *et al.*, 2006). The elderly have been shown to have higher levels of housing satisfaction than younger populations when other factors such as living space and property type are taken into consideration (H. W. Wahl *et al.*, 2009; Department for Communities and Local Government, 2015). This provides some evidence as to why being able to stay in their home is a highly important outcome for elderly people.

### **2.3.6 Concluding thoughts on aging at home**

The evidence shows that older people place a great importance on staying at home in a familiar environment where they can feel a strong sense of control over both their environment and also their activities. There remains, however, a paucity of evidence into the effect of the home physical environment on healing and well-being in old age. When functional problems occur, it affects the level of control that people feel in their

home by limiting actual and perceived choice. Impairment can be influenced by changes in both the number and magnitude of environmental challenges faced by the individual. There remains a lack of research on how these feelings change through ill health where people experience an internal loss of control. Furthermore, can mood and health can be improved by the interior design concepts, architecture and ambient features as has previously been shown in inpatient settings?

## 2.4 Residential and supported care design

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Some people are either unable to or choose not to stay at home as they age. For these there are three main options to meet their ongoing accommodation needs:

1. Move in with others, usually family or friends. In the UK in 2015 nearly 300,000 households were inhabited by more than one family, this was predicted to rise due to the increase of older parents moving in with their children and grandchildren.
2. Supported living facility: These are also known as warden controlled accommodation or extra care. Residents either buy or rent property which takes the form of bungalows, flats or bed-sits within a larger complex. All offer increased support but the amount available varies between properties. Some offer formal carer support and most have call alarm systems. Larger schemes have large communal spaces, shops, hairdressers and hobby areas.
3. Twenty-four hour care provision. There are two main types:
  - Residential care: Accommodation is rented via a weekly fee which includes a room and all meals and services. Carers are present 24 hours a day to assist where necessary. Residents need to be largely mobile and only require assistance with certain tasks. Apart from the bedroom, all areas are communal (Care Quality Commission, 2018)
  - Nursing home care: Trained nursing staff are present 24 hours a day. Rooms are rented and all services are provided. Each resident has either a private or shared bedroom and all other areas are communal. They care for people with a high level of need and who may require assistance with all ADLs (Care Quality Commission, 2018)

In 2011, 3.2% of those aged over 65 resided in care homes, this had remained stable over the preceding ten years despite a growth in the numbers of people over 65 rising by 11%. (Office for National Statistics, 2014).

This section of the literature review will focus on supported living facilities and twenty-four hour care settings which will be described under the heading of Residential Care.

Evidence-based design for residential care tends to reflect aspects of design for acute healthcare design: the provision of privacy, control and homelike environments (Marquardt, Bueter and Motzek, 2014). Indeed Residential Care Home design is centred on the need to make the environment as close to that of a domestic property as possible, as this has been found to reduce the disorientating effect of large multi-purpose spaces (Torrington, 2006).

It has been found that PwD living in nursing homes with higher quality physical environments maintain walking ability and eating ability for longer (Slaughter and Hayduk, 2012). Factors linked to good design in this study were privacy, choice, familiar furniture and décor and safety. They also found that private 'for profit' nursing homes had the poorest quality environments and publically owned had the best. This was a Canadian study involving participants (n=120) from fifteen nursing homes which did not specify any specific design elements. Poor design has also been linked with increased agitation and confusion (Pollock and Fuggle, 2013) This is in agreement with (Van Hoof and Kort, 2009) who state that limited layouts of living space can cause anxiety, insomnia and depressive feelings.

### **2.4.1 Privacy**

In research investigating the effects of graduation of space in residential care facilities, Barnes (2006) found that residents (n=452) who had a choice over space with different levels of privacy in which to spend time had a higher level of well-being. The results also showed that people with lower levels of dependency spent more time alone in their rooms which led to improved levels of environmental control and an increased time in active behaviour. However, there was no attempt in the research to separate levels of well-being from dependency, therefore it remains unclear whether improved well-being is due to privacy or maintained independence.

### **2.4.2 Legible Rooms**

Research by Torrington, (2006) found that in communal residential homes in Sheffield and Rotherham (n=38) residents and carers reported increased stress and confusion

created by large social areas. They report that although the majority of residential homes had chosen domestic style décor and fittings the size of the room and number of inhabitants often led to increased confusion, for example the dining room was mistaken for a café or a school.

The importance of creating easily understood rooms is also highlighted by the Dementia Services Development Centre, Stirling, UK. In their guidelines for designers it is repeatedly reemphasised that spaces for PwD should be made meaningful through the use of appropriate furniture and fittings (Fuggle, 2013).

### **2.4.3 Artwork**

Art in the residential care environment can benefit residents in a number of ways. The use of bright murals depicting recognisable scenes can be used for orientation and to provoke memories thereby creating a catalyst for social interaction. Reporting the results from a project in Japan, Chang, Lu, Lin, & Chen. (2013) found that although the large murals on the walls of the nursing home did not improve scores relating to the areas being “pretty and pleasurable” they were found to score highly for their ability to recall old memories. As an adjunct to the reports on the artwork, it was also reported that residents felt happier when in sunny rooms.

Although the use of large artwork and murals appears to have beneficial effects on recall of memories, the research does not indicate the relative ages of the participants. It is possible that different generations of residents will have different life experiences and may show differing responses to scenes depicting previous eras.

### **2.4.4 Outdoors**

Whilst there is evidence as to the benefits of being outdoors to promote health and improve well-being, access to outdoor spaces for residents of long term care facilities has been found to be limited. Dahlkvist, Nilsson, Skovdahl, & Engström, (2014) used questionnaires given to home managers (n=87), staff (n=667) and residents (n=415) to investigate the design of garden and the perceptions of the outdoor spaces provided by residential homes. The main finding was that although it was possible to

access the outdoor space from all homes, in 79% of homes there were obstacles which made walking around the space or effectively accessing the space independently impossible. Other problems discussed were a lack of suitable seating which again made the use of space extremely difficult for the residents (Dahlkvist *et al.*, 2014)

#### **2.4.5 Concluding thoughts on design in residential and supportive care**

In many ways design within residential care homes reflects aspects of that studied in acute health settings such as hospital wards. There is a compromise between the level of support and safety residents need and the ability of the environment to provide privacy, control and interaction. However, in contrast to the acute medical environment, residential care needs to reflect that it represents a long term domestic setting for those who reside within and therefore should feel homely. As discussed previously, homely is a subjective term and means different things to different people which led to difficulties in creating 'homely' attributes in their design.

The section on Aging in Place explained that evidence highlights that there is a preference to stay at home into old age, this means that for many, the act of moving into residential care represents a compromise away from their preferred residence.

### **2.5 Where PwD live**

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Dementia is progressive and life limiting, the rapid or gradual decline in cognitive and physical functioning means that people living with dementia find themselves spending time in a number of different settings: Acute elderly care medical wards, mental health elderly care units, acute adult mental health units, residential and nursing homes, hospices and their own homes (Torrington, 2006; van Hoof, Kort and van Waarde, 2009).

Two thirds of PwD live their own home, the other third in care homes (Andrews and Molyneux, 2012). Of those in their own homes one third live alone (Alzheimer's Society, 2014). The Alzheimer's Society report 'Support, Stay, Save' (Quince, 2011)

found that 83% of PwD rated being able to remain living in their own homes as very important. They further reported that this can be achieved with the right level of social support and if they live in a physical environment that meets their needs (The Alzheimer's Society, 2011; Alzheimer's Society, 2014). There has been a recent shift in housing focus for PwD across both the UK and Europe away from institutional care towards community support (van Hoof, Kort and van Waarde, 2009). The NICE Dementia guidelines (2006) state that all people with a diagnosis of dementia should have an assessment of their physical environment including *"environmental modifications to aid independent functioning, including assistive technology"* (NICE, 2006). However, crucially the guidelines do not specify when this assessment should take place or by whom.

Creating functionally enabling environments needs to take into account the changing health problems of the largely older patient group. 72% of PwD have other comorbidities such as impaired vision, hearing and balance (Pollock and Fuggle, 2013; Alzheimer's Society, 2014).

The National Dementia Strategy underlines the importance of both the home and service users in providing dementia care,

*"Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services"* (Department of Health, 2009).

Good design can assist PwD to remain living at home for longer. This is achieved through alleviating the effects of the disease process to prevent impairment and improving symptoms related to the disease. For new build projects there are guidelines available to assist the production of dementia friendly environments (Andrews and Molyneux, 2012; Fuggle, 2013). However as previously described, older

people frequently wish to remain in accommodation that they have occupied for many years, therefore these need to be modified to meet the changing needs of the inhabitants.

## 2.6 Home adaptation: Changing the home to meet changing needs

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A common way of meeting environmental challenges felt by older people at home and to prevent admission to residential care is the adaptation of the physical environment (Fänge and Ivanoff, 2009; Powell *et al.*, 2017). Housing is normally chosen for its ability to house a family and support them in middle age without consideration of older age. Therefore, the decision to 'Age in place' means that older people frequently find themselves in housing that needs adaption to meet their changing needs (Hwang *et al.*, 2011). The presence of home adaptations has been found to positively correlate with an increased time spent living in a property into old age. The English housing survey 20014-15 found that 40% of homes containing at least one person over 65 years old with a long term condition felt that they needed at least one house adaptation (Department for Communities and Local Government, 2015)

In an analysis of the UK data from the ENABLE-AGE study, Hwang *et al* (2011) found that housing modification and type of habitation such as living with family or owner occupier were the factors which most closely predicted the ability to age-in-place and therefore prevent early admission to long term care. However the study falls short of investigating the effects of the wider community and issues relating to the uptake of housing adaptations.

There is a body of research that shows the value of risk assessment and environmental modification to prevent injury, the most frequent cause of which is falls (H. W. Wahl *et al.*, 2009; Gillespie *et al.*, 2012; Eriksen, Greenhalgh-Stanley and Engelhardt, 2015; Powell *et al.*, 2017). There is evidence of a link between the home environment, usability and environmental changes that increase functional ability. Usability in the home focusses on function and how well an environment supports Activities of Daily Living (ADLs) (Iwarsson *et al.*, 2009) Home adaptations are commonly used to assist,



prevent falls and maintain independence in the home. This is a reflection of the fact that housing adaptation is most frequently triggered by an acute episode of illness rather than slow decline (Lansley *et al.*, 2005). Health and Social care professionals such as Occupational Therapists, Physiotherapists, Nurses and Social Workers are the people most commonly responsible for assessing and ordering housing adaptations (Mountain and Way, 2012).

### **2.6.1 Types of Home adaptation**

According to Pynoos, Steinman, Nguyen and Bressette (2012) there is evidence that home modification strategies for falls prevention can be split into four categories:

- Additive: for example ramps and grab-rails are usually implemented by healthcare professionals and incur costs in order to fit.
- Subtractive: easier to complete as they require removal of hazardous items such as rugs and clutter
- Transformative: can be small changes such as rearranging furniture, or large, such as widening doorways.
- Behavioural: change the way an individual uses their home such as creating a downstairs bedroom to remove the need to use the stairs (Pynoos *et al.*, 2012).

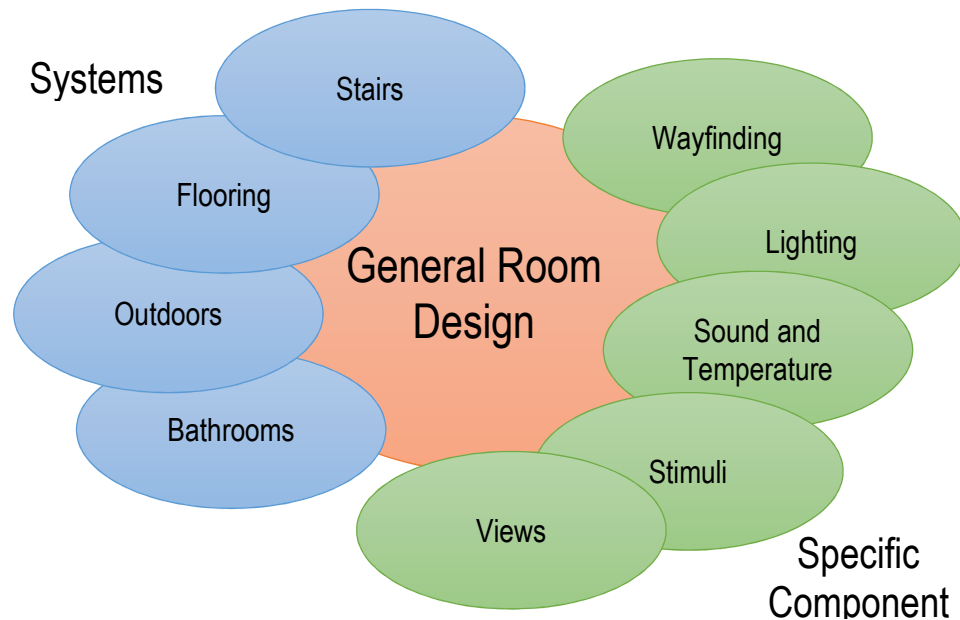
Limitations in mobility traditionally result in the most expensive adaptations such as widening doorways, provision of hoist equipment and installing ramped access, these adaptations are also most limited by the design of the property (Lansley *et al.*, 2005).

### **2.6.2 How home adaptation can influence the lives of PwD**

Traditionally housing adaptations for dementia have focussed predominantly on safety, avoiding falls and promoting safe transfers. More recent research has highlighted specific design factors that can increase quality of life, promote carer ease and reduce impairment (van Hoof *et al.*, 2013). Environmental change is now seen as an important adjunct to more traditional forms of therapy for dementia. There is now extensive evidence regarding the overuse of antipsychotic medication in Alzheimer's disease. The side effects of which include an increased risk of falls (Huang R. *et al.*,

2012). It has been shown that in 50% of patients, non-pharmacological modalities such as environmental modification and talking therapies, are more effective at reducing psychotic symptoms (in dementia) than antipsychotic drugs.

PwD have identified that home adaptations that help to mitigate risks at home are an important modality in the prevention of crisis and admission to hospital. In their study, Toot et al. (2012) used PwD, their informal carers and health care professionals to participate in focus groups to discuss causes of crisis for those living at home and what is the most effective way to prevent crises. PwD rated home modification and assistance by family and friends above professional healthcare interventions for the prevention of crises at home (Toot et al. 2012). There are many areas in which the home can be modified to influence the lives of PwD. The diagram in **Error! Reference source not found.**, outlines the aspects that will be covered here. As can be seen, the evidence fits into two broad areas, systems and then more specific components. Each particular design change cannot be viewed individualistically as each has an influence on other aspects which is shown by the overlapping sections of the diagram.



*Figure 3 Evidence based design aspects for dementia*

Dementia specific evidence-based recommendations for adaptations within domestic dwellings are summarised in Table 1. These recommendations are then discussed in greater detail in the text.

Type	Evidence based design	Source
General room design	Rooms that have a clearly defined purpose e.g. a dining table to demote that a room is for eating in, can aid intake and prevent wandering	van Hoof, Kort and van Waarde, 2009
	Lighting which highlights different areas of a room can aid perception	Torrington and Tregenza, 2007
Colour	Using furniture that is a contrasting colour to the surroundings makes it easier to recognise and helps to mitigate for perceptual changes	McNair <i>et al.</i> , 2013; Pocklington, McCabe and Dawson, 2014 Salamone <i>et al.</i> , 2009
	Avoid heavy patterned walls and flooring as reduced depth perception in dementia leads to a perception of uneven surfaces and impaired balance	Perritt, McCune and McCune, 2005
Visual Cues	Keeping a sightline between a PwD's chair or bed to the toilet enables wayfinding and toileting skills to be maintained	Marquardt, Bueter and Motzek, 2014
	Transparent panels in cupboard doors, can increase food intake as they allow individuals not to rely on memory	Torrington, 2009; Andrews and Molyneux, 2012
	Signs placed on cupboards and room doors should have both a picture and words to aid understanding for PwD	Scialfa <i>et al.</i> , 2008
Bathroom	Should have space for two people due to need for carer assistance as dementia progresses	Cohen-Mansfield and Parpura-Gill, 2007 van Hoof <i>et al.</i> , 2013
Temperature	PwD can have impaired auto-regulation of body temperature, therefore automated and responsive thermal control systems are needed to regulate temperature remotely.	van Hoof <i>et al.</i> , 2010
Flooring	Junctions between flooring and in doorways cause freezing and disturbed gait in dementia with Lewy bodies, therefore they should be avoided	Azulay, Mesure and Blin, 2006 Perritt, McCune and McCune, 2005
External views	Placing seating with a view of the outdoors, especially the wider community improves mood and connection to the community	Torrington and Tregenza, 2007 De Witt, Ploeg and Black, 2009
Stimuli	Reduced ability to respond to multiple stimuli in dementia leads to increased risk of falling. Environment which are kept free of distractions by removing clutter and reducing noise lead to fewer falls.	Marquardt, Bueter and Motzek, 2014 Bier <i>et al.</i> , 2017
Gardens	Being able to access the outdoors and nature improves mood in dementia	Lawton, 2001 Stark <i>et al.</i> , 2013
	Keeping well defined paths assists with wayfinding	Lawton, 2001

*Table 1 Summary of evidence based design for dementia in domestic dwellings*

### 2.6.2.1 General room design

The overall design of rooms in the home should assist PwD to overcome difficulties stemming from both their physiological and their cognitive deficits. Having a choice over space has been found to be important to residents and carers (Innes, Kelly and Dincarslan, 2011; Slaughter and Hayduk, 2012). Rooms should have a clear purpose and appear homely.

One of the predominant symptoms of dementia is a reduction in short term memory, therefore it has been suggested that fixtures and fittings could assist with mitigating reduced memory by:

- Being traditional in design to reflect those used by the person in early adulthood. This aims to reflect a period of time that is easier to recall and therefore can assist with recognition of purpose
- Having a clear purpose. The function of objects or furniture should be intuitive and obvious for example taps are better if a traditional cross head design and hot and cold are separate (Van Hoof and Kort, 2009).
- Being in a contrasting colour. Furniture is more readily used and recognised if in a differentiating colour or design to the floor and walls (McNair *et al.*, 2013; Pocklington, McCabe and Dawson, 2014).

### 2.6.2.2 Lighting

There are two main focusses of research into lighting levels and dementia:

1. Lighting for safety and wayfinding.
2. Lighting to affect challenging behaviour such as poor sleep-wake cycles and agitation.

#### 2.6.2.2.1 *Lighting for safety and wayfinding*

As eyes age they start to lose their ability function at the same level as when younger. The lens becomes thicker and less transparent, becoming more yellow in colour. This has the effect of reducing the amount of light that can pass into the eye, which in turn reduces the amount of light reaching the retina at the back of the eye. The effect of

this reduction in retinal illumination is a generalised lack of perceived light from the surroundings (Torrington and Tregenza, 2007; McNair *et al.*, 2013). While this means that older people can benefit from increased light levels (up to three times that of younger people), glare can also be a source of overstimulation (Pollock and Fuggle, 2013; Benbow, 2014) and distort depth perception (Andrews and Molyneux, 2012).

The time taken for the eye to adapt to changes of light is longer in the aging eye (Torrington & Tregenza 2007). Lighting which is more uniform in its application can help by putting smaller demands on the adaption ability of the eyes. However there is disagreement in the literature as to which approach is of the most benefit to older PwD: The older eye benefits from a uniform lighting approach, however, PwD have been shown to benefit from higher contrast and highlighting of areas where tasks are to take place (Torrington and Tregenza, 2007).

#### *2.6.2.2.2 Lighting to affect challenging behaviour*

Dementia can cause symptoms which manifest as challenging behaviour. Wandering, agitation, and aggression all create difficulties in caring for and supporting independence in people living at home. Circadian rhythms are biological processes within the body that respond on a 24-hour cycle. It is thought that they are influenced predominantly by light and dark stimuli. Whilst changes in circadian rhythms are a normal part of aging, the changes are amplified in dementia. Changes in circadian rhythm can lead to disturbed sleep-wake cycles characterised by frequent waking and activity at night and frequent napping during the day (Forbes *et al.*, 2014).

Improved lighting has been linked to improved sleep-wake cycles, improved physical activity (Chang *et al.*, 2013; Anderiesen *et al.*, 2014) and improved dietary intake during mealtimes (J van Hoof *et al.*, 2010). Natural light shows greater improvement than artificial light. Higher levels of environmental light (2500 lux or higher) in the morning or all day significantly increases the minutes of sleep at night in people with mild to severe dementia, with the greatest improvement found in the severe dementia group (Sloane *et al.*, 2007). However, this study found no conclusive evidence on changes to daytime sleepiness and it is not clear how the changes to lighting were

made, whether through natural or electric light or a mixture of both (Sloane *et al.*, 2007).

Table 2. Summarises changes that occur to vision through both the aging process and dementia specifically. These changes occur at both a physiological and a perceptual level. Bright light therapy is a specific treatment modality which aims to reset circadian rhythms by exposing people to dramatically increased levels of light within their visual field for specified lengths of time. The Cochrane Collaboration conducted an extensive review into the evidence for use of bright light therapy for improving cognition and reducing challenging behaviour in dementia. They found that there was a lack of good quality evidence (n=10 meeting their criteria) for the use of bright light therapy for a range of challenging behaviours (Forbes *et al.*, 2014). The main reasons given for the lack of evidence was that there was a large variation between the types, intensities and durations of light therapy given, intervention groups varied in their proportions of different types of dementia. It was also noted that only one study was based in the community, therefore the review recommends that more studies are needed to investigate the effect of light therapy both on PwD and their informal carers.

Change	Result	Functional Problem	How design can help
<ul style="list-style-type: none"> <li>• Lens thickens and loses transparency, becomes more yellow in colour (Behrman, Chouliaras and Ebmeier, 2014)</li> </ul>	<ul style="list-style-type: none"> <li>• Less light reaching retina and more blue light absorbed</li> </ul>	<ul style="list-style-type: none"> <li>• A darker view of the surroundings</li> <li>• Less able to discriminate blue colours (McNair <i>et al.</i>, 2013)</li> <li>• Disturbed circadian rhythms due to reduced luminance reaching the retina (Behrman, Chouliaras and Ebmeier, 2014)</li> </ul>	<ul style="list-style-type: none"> <li>• Provide lighting to at least three times that of normal.</li> <li>• Use colour from the red/orange area of the spectrum.</li> <li>• Use natural light where possible and light according to diurnal rhythms, keeping the daytime bright and the night-time dark.</li> </ul>
	<ul style="list-style-type: none"> <li>• Slower adaption between light and dark</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty seeing well when moving between areas of light and dark</li> <li>• Confusion due to poor ability to see detail.</li> </ul>	<ul style="list-style-type: none"> <li>• Create areas of uniform light.</li> <li>• Avoid sudden changes from light to dark and visa-versa.</li> <li>• Avoid creating shadow, do not light from beneath.</li> </ul>
<ul style="list-style-type: none"> <li>• Increased scattering of light by optics of the eye.</li> <li>• Loss of muscle fibres holding the lens (Ciliary muscles)( van Hoof, Kort, Duijnste, et al. 2010)</li> </ul>	<ul style="list-style-type: none"> <li>• Increased Discomfort glare(the reflex action to look away from a light source and difficulty seeing due to glare)</li> <li>• Can be caused directly (from a light source) or indirectly (due to reflection)</li> <li>• Increased Disability glare: decreased ability to see tasks but does not cause discomfort.</li> </ul>	<ul style="list-style-type: none"> <li>• Creates difficulty in seeing detail and surface positions.</li> </ul>	<ul style="list-style-type: none"> <li>• Use matt surfaces.</li> <li>• Position lights so that they do not cause reflections.</li> <li>• Have multiple sources of light to decrease reflection.</li> </ul>



Change	Result	Functional Problem	How design can help
<ul style="list-style-type: none"> <li>Loss of ganglionic cells in the retina (Salamone <i>et al.</i>, 2009)</li> </ul>	<ul style="list-style-type: none"> <li>Retinal cell damage: Atrophy of photoreceptors (J. van Hoof, Kort, Duijnste, <i>et al.</i>, 2010).</li> <li>Raised contrast-sensitivity threshold.</li> </ul>	<ul style="list-style-type: none"> <li>Impaired colour discrimination – accelerated in Alzheimer's disease compared to normal aging (Salamone <i>et al.</i>, 2009)</li> </ul>	<ul style="list-style-type: none"> <li>Increase contrast between doors and walls and furniture and décor to assist with wayfinding and function.</li> </ul>
<ul style="list-style-type: none"> <li>Changes to the perception and interpretation of visual cues</li> </ul>	<ul style="list-style-type: none"> <li>Decreased depth perception.</li> </ul>	<ul style="list-style-type: none"> <li>Poor visuospatial skills</li> </ul>	<ul style="list-style-type: none"> <li>Avoid heavily patterned walls and flooring. Dark strips can be perceived as holes or trenches making difficult to cross.</li> </ul>

*Table 2. Changes in Visual ability in ageing and dementia*

### 2.6.2.3 Sound and Temperature

Research by Garre-Olmo et al. (2012) found that the quality of life of patients with severe dementia was affected by temperature light and noise. The study compared quality of life (QOL) and function scores across eight nursing homes in Spain. The main findings of the study were that higher noise in lounge areas was associated with lower QOL and reduced social interaction. They hypothesise that the ratio of temperature to hours spent in a bedroom correlated to QOL and that this may be due to a decrease in physical activity and circadian rhythms. However it must be noted that the sample contained a high percentage of people who had been physically restrained in beds (48.8%) or were bedbound (18.4%). For these residents other factors could be considered in relation to their quality of life such as restricted view and lack of social integration.

Dementia causes a reduction in an individual's ability to process auditory information which makes them prone to over stimulation. This can lead to agitation and increased confusion (Andrews and Molyneux, 2012).

Increased levels of noise and decreased personal space can cause increased agitation in nursing home settings (Joosse L., 2012). Studies show that sound levels are frequently highest in dining areas, where noise can have an adverse effect on dietary intake (Garre-Olmo *et al.*, 2012; Joosse L., 2012). Family and staff in long-term care facilities have identified levels of noise as one of the top two issues which have a negative effect on quality of life in long-term care for PwD (Garcia *et al.*, 2012). This was concluded from focus groups involving eight residential care homes across Canada. Noise was described as either nondescript background noise or that from televisions, other residents shouting or music (Garcia *et al.*, 2012). Minimising noise is one way of creating a homely atmosphere within a residential setting.

Changes in temperature can cause unwanted behaviour in PwD. The reasons for this are twofold; an individual may not have the ability to voice that they are feeling too hot or cold and take appropriate actions such as donning or removing clothing. Secondly there is evidence to suggest that dementia can damage the

thermoregulation areas of the brain which leads to an inability to auto-regulate body temperature (Van Hoof, 2008; J. van Hoof, Kort, Hensen, *et al.*, 2010). Therefore, PwD perceive environmental temperature differently to others. Thought should be given to the usability of thermal control systems in the homes of PwD with regard to their familiarity with the technology involved and the responsiveness of the system (J. van Hoof, Kort, Hensen, *et al.*, 2010). This study which combined a systematic review of the literature with qualitative data from two previous studies concluded that it remains unclear what the difference in perception is between the older population in general and PwD (J. van Hoof, Kort, Hensen, *et al.*, 2010).

#### **2.6.2.4 Flooring**

Junctions between two types or patterns of flooring (especially in doorways) can cause falls or difficulty mobilising as it may be perceived as a step. Dementia involving Lewy bodies is linked to Parkinson's disease in which people may experience freezing or difficulties initiating movement in doorways and on highly patterned flooring (Azulay, Mesure and Blin, 2006). Light reflective values (LRV) between the two types of flooring should be similar and threshold strips should blend in (Pollock and Fuggle, 2013).

Perritt, McCune, & McCune, (2005) investigated the effect of pattern and texture of carpet on walking time and stability in people (n=107) with Alzheimer's disease. They found that carpet with a large floral or a checkerboard pattern caused participants to sidestep and hold a handrail more frequently than carpet with a design of smaller contrast or plain. Their other findings relate to walking speed and pile. Carpet with a larger pile created slower walking speeds than a level loop texture. Walking speed has been found to be a predictor of mortality in older people. Therefore flooring that enables the maintenance of a quicker gait has wide reaching benefits (Hardy *et al.*, 2007).

#### **2.6.2.5 Wayfinding**

Due to memory loss and perceptual difficulties PwD frequently have difficulty navigating around space. Other symptoms such as agitation can also cause people to wander which can present problems regarding safety.

Visual acuity decreases in PwD which leads to reduced depth perception, contrast and an inability to discriminate texture (Pollock and Fuggle, 2013). Shiny floors, mirrors and patterned surfaces should be avoided (Pollock and Fuggle, 2013; Benbow, 2014). Doors to rooms that have contrasting colours to the walls and have individual designs that can assist with way-finding. Colour contrast is more evident in the yellow and red areas of the spectrum with the blue and purple areas perceived less strongly (Torrington and Tregenza, 2007; Marquardt, Bueter and Motzek, 2014).

Toilets that are viewable from a person's bed or chair can prompt use and decrease confusion (Marquardt, Bueter and Motzek, 2014). Visual cues can assist in residents maintaining ADL independence (Van Hoof and Kort, 2009; Innes, Kelly and Dincarslan, 2011). They also found that having names on doors, doors highlighted by other landmarks helped residents find their own bedrooms. A study by Scialfa et al (2008) investigated the effect of cognitive impairment on sign comprehension. They found that when signs contained both icons and text they were successfully interpreted on significantly more occasions than sign which included only icons. They concluded that this was due to icon recognition requiring a higher level of perception and memory than text (Scialfa *et al.*, 2008).

Transparent panels in doors and cupboards can assist functional use by reminding patients what is behind them (Andrews and Molyneux, 2012). It is hypothesised by Torrington (2009) that PwD use visual cues to identify where they are as they cannot rely on memory. For this reason a room should have an obvious function so that its use cannot be misunderstood (Torrington, 2009). To assist with identification of differing room functions, lighting can be used in a systematic way to create distinct areas (Torrington and Tregenza, 2007). However, there is a lack of empirical evidence as to the effectiveness of these recommendations in reducing functional impairment in PwD. Therefore this represents an opportunity to investigate how PwD use sensory cues to assist them in functioning and how effective these recommendations are in reducing impairment in dementia.

Design can be used to prevent wandering residents from entering unsafe areas such as kitchens or storage rooms. Doors that are similar in colour to the walls will be less easy to find and wide dark flooring strips are less likely to be crossed as they are perceived as a large gap (Letts *et al.*, 2011; Benbow, 2014; Marquardt, Bueter and Motzek, 2014). The Cochrane Collaboration review into non-pharmacological interventions to prevent wandering in dementia at home found very limited evidence of limited quality (no randomised control trials) and therefore they were unable to draw any conclusions on best practise. This was mainly due to the studies that were observational in nature (Hermans, Htay and Cooley, 2007). Additionally ethical issues exists in the design of spaces in such a way as to prevent exit or access. For example, is it ethical to camouflage doors, which effectively uses an individual's own symptoms to contain their activity?

#### **2.6.2.6 Bathrooms**

Having an en-suite bathroom could increase the visibility of a toilet from the bed but there is disagreement in the literature on the importance of en-suite bathrooms for residents with dementia. In their study, Innes *et al.* (2011) found that care home residents and their families did not feel that this was important as residents tend to spend most of their time away from their bedrooms. Additionally when people did use bathroom facilities they were always assisted by staff therefore wayfinding in this way was not seen as important, the emphasis being on good quality communal facilities. However, being able to see a toilet from the bed has been advised as a way to promote continence overnight in PwD as it serves as a visual prompt (van Hoof *et al.*, 2013). This is most easily achieved by the presence of en-suite facilities.

Bathrooms, present a compromise between privacy and safety. The bathroom's environment predisposes it to risk of slips, falls and drowning. PwD frequently require assistance in the bathroom with aspects of personal care which means it should have space to allow for two people (Cohen-Mansfield and Parpura-Gill, 2007; van Hoof *et al.*, 2013).

Bathroom doors should be a different colour to other internal doors to assist in recognition (Pocklington, McCabe and Dawson, 2014) , routes to the toilet should be clutter free and signage which provides a visual cue such as a picture on the door can help with identification (J van Hoof *et al.*, 2010)

Increasing the temperature of bathrooms has been shown to increase compliance with bathing and a reduction in aggressive behaviour during personal care tasks in nursing homes (Cohen-Mansfield and Parpura-Gill, 2007; J. van Hoof, Kort, Hensen, *et al.*, 2010). However no specific temperature range data was provided in either study.

#### **2.6.2.7 Stairs**

Ascending and descending stairs is one of the most physically challenging activities in the home and therefore carries the most risk of physical injury. Designing stairs to reduce falls in the elderly was investigated by (Afifi, Parke and Al-Hussein, 2014) who concluded from their review of previous literature that there are five important elements in the design of staircases, as described in Table 3. Although these results are useful in the assessment of the home environment, it should be noted that it is extremely unlikely that the geometric and step design could be adapted within the home in order to influence aspects of safety and are more likely to be considered in the design of new homes. Furthermore the literature review undertaken was not specifically for PwD rather it included older people, however, due to dementia predominantly being a disease of older age and one which creates a largely increased risk of falls the findings are pertinent to this review.

It is frequently advised by healthcare practitioners that where possible bedrooms are moved downstairs to eliminate the need to use stairs (J van Hoof *et al.*, 2010). However due to poor short term memory PwD frequently may use the stairs regardless of alterations to the living arrangements within the home as they are unable to recall recent changes. Another common way individuals use to avoid having to use the stairs is the addition of a stair-lift, but again this requires an individual to both remember a new routine and be able to use new technology. A permanently fitted

stair-lift also narrows the stairs for other member of the household, causing a potential trip hazard.

Design element	Key features / types	Optimal design for safety	Poor design for falls prevention
Geometric design	Configuration	U-shaped and those which offer a landing part way to allow for rest.	Spiral, helical and composite stairs
	Number of steps	Stairs of 10-12 steps	Flights over 12 or under 6 steps.
Step / tread design	Going depth (depth of tread without nosing)	Between 280-330 mm	More than 330mm
	Riser height	Between 152-190mm	More than 190mm or less than 152mm
	Nosing	Rounded edge 15-25mm depth.	Non-rounded
	Finishing material	Uniform slip resistance, cohesive	Non cohesive covering
Lighting	Illumination	More than 300 lux	Less than 300 lux
	Consistency	Uniform	Non uniform (light/dark patches)
	Light switches	Positioned away from staircase and two-way	In path of stairway and one-way
Handrails	Existence	Two rails one either side of stairway	No handrail
	Height	910-970mm high	Lower than 910mm or higher than 1000mm
	Cross-section	Circular: circumference 100-160mm or Oval: 50x37mm	Other designs reduce the ability to grip and user comfort
	Surface texture	Neither smooth nor rough	Very smooth or very rough
	Extension	More than 480mm from last step on at least one rail	Less than 320 on one rail
	Handrail-wall clearance	Smooth wall and more than 57mm clearance	Rough wall and less than 75mm clearance

(Affi, Parke and Al-Hussein, 2014)

*Table 3. Optimal Staircase design for falls prevention*



#### **2.6.2.8 Views**

Seating with good external views especially of the community or entrances and exits are preferred (Torrington and Tregenza, 2007; Innes, Kelly and Dincarslan, 2011). Allowing views of external activities is one way of involving people in a wider community (Lawton, 2001) and mitigates the loss of accessibility to the outside space (De Witt, Ploeg and Black, 2009). Torrington & Tregenza, (2007) also found that older people living in their own homes exhibit protective behaviour of their views. Although they go on to consider that there is a lack of evidence into the effect of natural views in PwD.

#### **2.6.2.9 Outdoor**

Spending time outside has far reaching health benefits, physiologically the body relies on sunlight for vitamin D production. Vitamin D is necessary for the absorption of calcium and the prevention of osteoporosis. Activities that are made more accessible by being outdoors such as exercise and horticulture have also been shown to improve agitated behaviour in dementia.

Outdoor space should be able to be accessed without having to ask for permission or assistance (Innes, Kelly and Dincarslan, 2011). Exercise has been shown to improve symptoms of dementia and delay progression, so outdoor space should allow for meaningful exercise (Anderiesen *et al.*, 2014). Well defined paths assist with way-finding. An important aspect of outdoor space is to provide a place to walk to, thus giving a meaning to exercise and increasing functional motivation (Lawton, 2001).

#### **2.6.2.10 Stimuli**

Whilst some controlled environments such as the multisensory room (Snoezelen) can allow PwD to experience stimulus with minimal cognitive input (Maseda *et al.*, 2014), the presence of multiple stimuli may affect their ability to respond to other external factors. There is a risk of over stimulation in dementia, caused by an individual's inability to process multiple sources of sensory feedback simultaneously. This leads to disorientation and increased confusion (van Hoof, Kort, Duijnsteet, et al. 2010).

A further way in which increased stimuli can be detrimental to older people and those with dementia is due to their reduced ability to dual-task. The principle of dual-tasking relates to the ability to perform two tasks simultaneously or respond to external stimuli whilst completing a second functional task (Bier *et al.*, 2017). In older people, following stroke or dementia the ability to dual-task can be dramatically reduced. A reduced dual task ability is strongly correlated to a risk of falling. Environments which place higher sensory demands through aspects such as noise, TVs or clutter, reduce an individual's ability to mobilise safely (Muhaidat *et al.*, 2010; Bier *et al.*, 2017), however rooms with brighter lights and a larger variation in sound levels have been shown to increase wandering behaviour (Algase *et al.*, 2010). The combined effects of an increase in wandering behaviour but a decrease in ability to do so safely means that these types of environment present a high risk of injury. Environments which reduce distraction from external stimuli show improved care outcomes (Marquardt, Bueter and Motzek, 2014).

### **2.6.3 CONCLUDING THOUGHTS ON DESIGN FOR DEMENTIA**

The evidence and recommendations for improving design of the physical environment in order to reduce impairment in dementia is wide ranging. Much of the available research has focussed on the design of residential care settings as this represents a more controllable environment. Some of the recommendations are readily transferred to the domestic setting such as the provision of artificial light and appropriate flooring, however, for other changes such as the provision of multisensory stimuli and wayfinding prompts there is little or no evidence as to how this can affect behaviour in the home.

## **2.7 Achieving Home adaptation in domestic environments**

### **2.7.1 The Implementation of Home adaptation**

It has been reported that while residents can feel that housing adaptations increase their ability to perform activities within the home and their social interaction, in practice housing adaption was rarely optimal and required updating over time (Pettersson,

Löfqvist and Malmgren Fänge, 2012). They also found that participants wanted adaptations to be aesthetically pleasing as well as functional. Participation in activities outside the home can also be positively influenced by a programme of housing adaptation. In a pilot study, Niva & Skär (2006) found that participants reported an increase in the opportunities to perform in leisure pursuits following access adaptations made by an Occupational Therapist (OT). However they also found that whilst access to the home and areas used for ADL completion were addressed by the OT, adjacent areas such as laundry rooms and storage rooms were not. This impacted negatively on living space and freedom of movement for the individuals.

In a similar study to the one outlined above, Aplin, Jonge, & Gustafsson, (2015) found that there was disagreement between participants (n=42) in Australia, with some feeling that home adaptations had made their home feel like a hospital, whilst others were not concerned with the aesthetic appearance as long as they fulfilled their practical purpose. Participants who had received major home modifications through government or community services were interviewed using a semi-structured format. Problems described in the interviews were a lack of control over the home modification process and a reduction in home safety linked to amassing a large amount of equipment in the home which caused trip hazards and a reduction of living space (Aplin, Jonge and Gustafsson, 2015). Neither the research by Pettersson et al., (2012) and Aplin et al., (2015) specifically concentrate on the elderly, instead homes in need of adaptations due to impairment by both adults and children. The studies also took place in Sweden and Australia respectively. Health and Social care systems differ widely between countries and it is likely that this affects the generalisability of the results.

In a novel project, Eriksen, Greenhalgh-Stanley and Engelhardt (2015) completed a retrospective study on how home safety modification affects falls and function. Their approach was to study the effect that early home adaption has on independence and function by investigating the effect of home adaptations present in the home of widows. The adaptations were initially completed due to the needs of their now deceased spouses. Their data showed that safety adaptations reduced falls and can

reduce number of nursing home stays. They were unable to hypothesise, however, which adaptations made the most difference and whether the modification of the home was cost dependent (Eriksen, Greenhalgh-Stanley and Engelhardt, 2015). Their findings are interesting as they add evidence to the theory that early home adaptation has a prophylactic effect on falls and impairment.

Therefore, home adaptation can improve the functional use of the home into old age and prevent admission to long term care, however, the utilisation of home adaptations is dependent on people either proactively making changes to their home or following the advice of professionals. A study by Gerson, Camargo and Wilber (2005) looked at the incidence of patients aged over 65 years, making fall reduction home adaptations following attendance to an emergency department. They found that there was no statistical difference in number of people making home adaptations after receiving printed advice on discharge and those who did not. The amount of older people making modifications at 1 month follow up were low 8% for the intervention group and 9% for the control group (Gerson, Camargo and Wilber, 2005). There were several methodological restrictions such as small sample size, and only 23% of the control group completing the follow up telephone questionnaire. The inclusion criteria did not specifically target people who had a history of falls which may have accounted for the low take up of advice and reasons for non-uptake of advice were not investigated.

The poor implementation of home modification advice could also be due to lack of interest in making changes. A small study by Kruse et al (2010) found that there was a lack of motivation to make housing adaptation to prevent falls due to a lack of perceived risk. The housing adaptations in this study were recommendations from an OT. No data is given on the origins of the referral to OT and out of the 10 participants 9 were living with a spouse. Interestingly they found that older people were reluctant to enter into conversation discussing risk of falls and saw them as an inevitable consequence of aging (Kruse *et al.*, 2010).

A further explanation for the negative response to housing adaptation advice in the studies by Gerson, Camargo and Wilber, (2005) and Kruse et al (2010) could be the

nature of the advice offered. Both focussed on the prevention of negative events rather than the promoting and allowing beneficial effects such as improved access to social interaction or greater long term independence. Studies that interpret the effects of previous housing modification tend to report more positive findings as people have discovered renewed independence and control over their lives. This is supported by studies by Tanner, Tilse and de Jonge, (2008) and Niva and Skär, (2006) who found the impact of completed housing modifications was positive both functionally and served to support the meaning of home and reinforce self-esteem. Tanner et al. (2008) stress the importance of communication and listening to patients to allow them to keep feelings of control throughout the modification process.

Silverstein, Hyde, & Ohta, (1993) completed a study looking at how professional recommendations were implemented by care givers and patients with Alzheimer's disease. Their study also investigated the perceived barriers to implementation as experienced by nurse practitioners. The target problems of adaptations were categorised into four areas: Cognitive and behavioural impairments, safety, caregiver ease and impairments of ADLs. They found that 42.2% of recommendations were not implemented at all and 6.2% were only partially implemented. The most common reasons for not implementing changes were that the patient would soon be admitted to 24hour care (49 %) or that the caregiver did not believe the adaptation was necessary (44 %) (Silverstein, Hyde and Ohta, 1993).

However, the average time since diagnosis for the study was 4.16 years which may have increased the amount of patients awaiting 24hour care and the recommendations were mainly focussed on behavioural environmental changes such as where to store items or use of schedules. Recommendations regarding aesthetics of rooms, colour and lighting were limited and may reflect the age of the study (25 years).

In agreement with Silverstein et al., (1993) the most common reason given for rejecting modification advice was the feeling that it was not needed (29.8%) or not helpful (24.5%). The study concluded that more research is needed on how to improve

awareness for home adaptations in dementia and how to engage care givers to make environmental changes (Marquardt *et al.*, 2011).

The findings of the above study are further supported by a report from the Australian Housing and Urban Research Institute (2015). Part of the report involved interviewing 12 PwD-carer dyads on home modifications and assistive technologies. They found that bathroom modifications were the most common. Respondents indicated that bathroom modifications were made for two reasons: to enable independence or to promote safety. The carers interviewed highlighted that independent toileting was a priority, with several respondents describing both additive and behavioural modifications undertaken to assist with personal care tasks (Gabriel, Faulkner and Stirling, 2015).

Housing adaptations have the power to restore a sense of security in the home. A sense of safety and security has been shown to be a defining aspect of the meaning of home (Heywood, 2005). The need for privacy and control has been discussed in relation to the design of healthcare facilities (Section 3.1) but remains equally, if not more, important in the home environment. This is highlighted due to the trend in moving healthcare provision away from inpatient to domiciliary settings, therefore turning homes into acute healthcare environments. Heywood (2005) warns of the effects of a procession of healthcare workers into a person's home may be to erode the meaning of home for that person.

#### **2.7.1.1 The influence of informal carers**

Reports show that 79% of PwD live with a carer. Although it is also noted within the Alzheimer's Society report 'Support, Stay, Save' (2011) that these figures may be an overestimate as people living with carers tend to respond in higher numbers than those living alone (Quince, 2011). There is a body of research that has investigated the way in which carers cope with the burden of caring for a PwD on a daily basis. A study by Papastavrou *et al.*, (2011) found that positive coping styles such as problem solving were negatively associated with feelings of burden, indicating that carers who are more confident in finding solutions to the problems associated with dementia feel less

burden. However the study did not include specific problem solving approaches such as home adaptation.

The presence of informal carers positively influences the occurrence of home adaptations, especially when dwelling at the same address (Kim *et al.*, 2014). Their study also found that younger care givers were more likely to adapt the environment, which they hypothesise may be due to their ability to respond quickly to the needs of the older person. However the research was limited to a telephone questionnaire which measured housing adaption by a single closed question and did not explore the types of modifications made.

### **2.7.2 Concluding thoughts on home adaptation Implementation**

The current body of research indicates that individuals who adopt home adaptation have improved safety and independence. However, despite these benefits, previous research has found individuals are often reluctant to use home adaptations due to a lack of perceived need or belief that the adaptation will not help. It is interesting to note that younger carers who live with a family member with dementia were more likely to adapt the home. This could be due to the carer being able to objectify the changes and seeking ways to cope with increasing care demands.

## **2.8 Financial considerations of Home adaptation**

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There are two main financial considerations related to home adaptations:

- Whether home adaptations lead to reduced healthcare costs. Pertinent to the UK National Health and Social Services as the predisposing tenet of these is to provide treatment and equipment which is free at the point of care, including some home adaptations.
- The extent to which people are willing to pay for adaptations to their home. Linked to private healthcare systems which require users to purchase either insurance or specific items privately. This is also becoming more evident in the

UK due to disparities between the types of equipment available to purchase and the adaptations that are available from health and social services.

### 2.8.1 Reducing healthcare costs.

There are financial motivators for the change in healthcare culture away from an inpatient settings to the community. Dementia currently costs the UK over £26 billion (Lewis *et al.*, 2014). At any one time, up to 25% of acute hospital beds are occupied by PwD (Royal College of Psychiatrists *et al.*, 2013) who then have a length of hospital stay 22.1% longer than those of a similar age without dementia (CHKS, 2013). The extra bed days alone cost £83.8 million per annum (based on 2011 figures of £231 per hospital bed per night). Among the most common causes of acute admission for PwD are fractured neck of femur caused by falls, superficial injury contusion and other psychoses (CHKS, 2013). Research has shown (see section 2.1.1.6 Preventing falls) that the risk of falls and symptoms such as agitation and aggression can be mitigated through modification of the home environment.

A report derived from research evidence produced by the Centre for Better Ageing found that appropriate use of home adaptations could result in a 26% reduction in falls in the homes of people over 65 which would reduce the cost of health and social care to the UK government by £500 million a year. However, the only evidence of a return on investment is on the prevention of falls on stairs which was measured as a return of 62 pence for every £1 spent on adapting stairs for safer mobility (Powell *et al.*, 2017).

A further report focussing specifically on housing for PwD from the National Housing Federation (UK) recommends that the use of home adaptations and support services can promote living independently at home and support discharge from hospital. They state that a £1.6 billion investment in housing support services (including home adaptation) creates an annual cost saving of £3.41 billion through reduced length of stay and lower readmission rates. In the UK informal unpaid care for PwD living in the community is valued at £12 billion in 2010 (Luengo-Fernandez, Leal and Gray, 2010)



Health professionals such as OTs, specialist nurses and Physiotherapists can offer advice and provide supportive living aids (Mountain and Way, 2012). In the UK local authorities can provide adaptations up to the cost of £1000 (including cost of fitting) (AgeUK, 2017). However these adaptations frequently have strict referral criteria and incur long waiting lists. For adaptations that cost more than this patients may be charged or advised to arrange for the modifications privately. Tax relief is offered on some home adaptations made due to long term disability. For example, living aids such as adjustable beds, stair lifts and alarms as well as building work to add ramps, widen doorways, fit lifts, bathrooms and toilets are VAT exempt (HM Revenue & Customs, 2015a, 2015b)

In their paper, Chiatti and Iwarsson (2014) discuss the importance of separating the finance of housing adaptations which can be easily quantified, away from the costs which are more subjective. They conclude that the economics relating housing adaptation is a complex multifactorial area and requires further investigation to allow health professionals (OTs) and researchers to analyse the cost effectiveness of interventions (Chiatti and Iwarsson, 2014).

### **2.8.2 Willingness to Pay**

Willingness to pay (WTP) refers to the amount people are prepared to pay for a variety of interventions linked to their individual needs. Predominantly used in the US as a measure of acceptability of a service. Jutkowitz et al (2010) concluded that WTP is influenced more strongly by an intervention that reduces the time spent care giving than one which offers improvements in quality adjusted life years. Their study investigated financial savings that could be made by care givers purchasing a Tailored Activity Program for PwD which included a physical environment assessment. The study does not allow us to analyse caregivers WTP for home modifications alone or the relative cost of these (Jutkowitz, Gitlin and Pizzi, 2010).

There is a strong probability that the costs of and WTP for home modifications are influenced by different countries. Van Hoof et al (2009) found that even within neighbouring European countries there is a large disparity in the provision of services

for PwD and the social expectation of state funding for these (van Hoof, Kort and van Waarde, 2009). In the US there is no overriding source of funding for home adaptation. Options such as Medicare do not cover home modification or assistive equipment beyond mobility aids. Some services such as the Department for Veteran Affairs offer a structural alterations program for those who are eligible (Pynoos, Steinman and Nguyen, 2010). OTs in the US report that understanding the financial constraints of a service user was very important, they feel that it is inappropriate to discuss all potential home adaptations for a particular problem if it is clear that a particular client cannot afford to implement them (Stark L. *et al.*, 2015).

Aplin, de Jonge, & Gustafsson, (2013) found that home modification services in Australia often left service users wanting extra adaptations or improved functionality but that this was not achievable due to budget restraints. This meant service users either had a limited choice or faced paying for adaptations themselves. This was especially evident in the area of occupational interest; activities that were not directly linked to ADLs or basic personal care such as access to a garden or swimming pool were not available through occupational therapy and were purchased privately by clients, often placing them under a significant financial burden.

Jutkowitz *et al.*, (2012) attempted to determine the cost effectiveness of a home based intervention aimed at promoting independence and well-being in the US. The intervention included balance and strength training as well as occupational therapy visits to assess and provide home modifications. The average cost for home modifications within the scheme including labour costs of ordering and installing, was \$439 (approx. £287). This was concluded to be within an acceptable budget for service users and incurred fewer costs than more traditional forms of home treatment. This study specifically used participants without cognitive impairment, and the home modifications were predominantly used to prevent falls and promote mobility and access (Jutkowitz, Gitlin, Pizzi, Lee, 2012).

## 2.9 Sources of Information and Products

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As previously stated in Section 2.6, healthcare professionals have traditionally been the main source of home adaptation advice for older people (Mountain and Way, 2012). During an episode of acute care patients are assessed by therapists and given advice relating to a wide variety of home adaptations in order to assist with ADLs and prevent falls. In the UK most home adaptation advice is provided by OTs but may also be given by physiotherapists or nursing staff. During an assessment OTs consider a number of aspects which influence the advice they give such as: Readiness for change, Compliance, Finances, Personal and social support, Logistical issues relating to the house (Stark L. *et al.*, 2015). In this way an OT offers tailored solutions to functional problems following consideration of ability and need.

There is a growing range of literature and assistance for PwD and their families, especially on the internet. **Error! Reference source not found.** and Table 5 identify written sources of information commonly available to PwD and those involved in their care. It shows that a variety of charities such as the Alzheimer's Society, AgeUK and Home Improvement Agencies such as Care and Repair produce downloadable documents on a wide range of topics regarding dementia care including home adaptation and improvements (Mountain and Way, 2012; Care & Repair England, 2015).

Advice regarding home adaptation and equipment covers many areas, with no one source covering all aspect, **Error! Reference source not found..** The most common area covered by the information is adapting lighting to ease the symptoms of dementia, closely followed by telecare and assistive technology. Conversely, information regarding the financing of home adaptations was only found in two sources of information from AgeUK and therefore was not specifically targeted at people with dementia.

Title	Publisher	Format	Cost	Aimed at	Available at (URL)
Disability Equipment and home adaptations	AgeUK	Online – Print ready	Free	Older people	<a href="https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs42_disability_equipment_and_home_adaptations_fcs.pdf">https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs42_disability_equipment_and_home_adaptations_fcs.pdf</a>
Adapting your home: Services and Equipment to help you stay living at home	AgeUK	Online – Print ready	Free	Older people	<a href="https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig17_adapting_your_home_inf.pdf">https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig17_adapting_your_home_inf.pdf</a>
Caring for someone with dementia	AgeUK	Online – Print ready	Free	Carers	<a href="https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig47_caring_for_someone_with_dementia_inf.pdf?dtrk=true">https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig47_caring_for_someone_with_dementia_inf.pdf?dtrk=true</a>
Making your home a better place to live with dementia	Care and Repair England: Home improvement agency	Online – Print ready	Free	PwD and carers	<a href="http://careandrepair-england.org.uk/wp-content/uploads/2017/09/CRE-Silverlinks-SHGuide-Dementia.pdf">http://careandrepair-england.org.uk/wp-content/uploads/2017/09/CRE-Silverlinks-SHGuide-Dementia.pdf</a>
Equipment adaptations and improvements to the home	Alzheimer's Society	Online – Print ready	Free	PwD and carers	<a href="https://www.alzheimers.org.uk/get-support/staying-independent/equipment-adaptations-improvements-home">https://www.alzheimers.org.uk/get-support/staying-independent/equipment-adaptations-improvements-home</a>
10 Helpful hints for dementia design at home	Dementia Services Development centre (DSDC)	Book	£7.50	Carers	N/A
10 Helpful hints on heating and lighting for PwD and their carers	DSDC	Book	£7.50	PwD and carers	N/A
Designing Interiors for people with dementia	DSDC	Book	£22.50	Professionals	N/A

Choosing equipment to help with memory and safety	Disability Living Foundation	Online – Print ready	Free	Older people	<a href="https://www.dlf.org.uk/factsheets/safety">https://www.dlf.org.uk/factsheets/safety</a>
Making your home more dementia friendly	Dementia Care	Online	Free	Family and carers	<a href="http://www.dementiacare.org.uk/services/need-some-advice/making-home-dementia-friendly/">http://www.dementiacare.org.uk/services/need-some-advice/making-home-dementia-friendly/</a>
Home Environment and Dementia	NHS Choices	Online	Free	PwD and Carers	<a href="https://www.nhs.uk/conditions/dementia/home-environment/">https://www.nhs.uk/conditions/dementia/home-environment/</a>

*Table 4. Common sources of home adaptation literature*

### 2.9.1 Products

There is a growth in the market of assisted living devices. Pharmacies and specialist shops now offer a range of assistive equipment, these range from small devices to larger permanent fixtures and furniture (Pynoos, Steinman and Nguyen, 2010). Some larger high-street retailers also offer a limited range. These products are predominantly aimed at promoting safety and functional independence amongst older people living in the community rather than specifically for PwD. There has also been a recent growth in specific dementia care products and online shops specialising in living aids specifically for dementia.

Title	Living aids	Telecare / Assistive technology	Sight problems	Hearing problems	Noise	Signs/labelling	Financial assistance	Lighting	Colour	Retro decorating	Flooring	Remove clutter	Window view	Covering Mirrors	Keep objects in view	Handrails	Heating	Smoke/carbon monoxide detector	purposeful rooms	Eating / drinking	Outdoors and access	Furniture	Bathrooms and WCs
Disability Equipment and home adaptations	✓	✓					✓																
Adapting your home: Services and Equipment to help you stay living at home	✓	✓	✓	✓		✓	✓					✓											
Caring for someone with dementia	✓	✓						✓										✓					
Making your home a better place to live with dementia									✓	✓	✓	✓	✓	✓	✓								
Equipment adaptations and improvements to the home		✓						✓		✓		✓				✓	✓						
10 Helpful hints for dementia design at home			✓	✓	✓	✓		✓	✓	✓	✓	✓		✓		✓		✓	✓	✓	✓		✓
10 Helpful hints on heating and lighting for PwD and their carers			✓	✓				✓									✓						
Designing Interiors for people with dementia			✓	✓		✓		✓	✓		✓	✓		✓	✓	✓			✓		✓	✓	✓
Choosing equipment to help with memory and safety	✓	✓						✓				✓						✓					
Making your home more dementia friendly	✓	✓			✓	✓		✓	✓					✓	✓	✓		✓			✓	✓	✓
Home Environment and Dementia	✓				✓	✓		✓	✓		✓			✓							✓	✓	

Table 5 Topics covered by home adaptation literature

### **2.9.2 Concluding thoughts on information and products for PwD**

There appears to be a dichotomy between the provision and usefulness of information provided regarding home adaptation. Information produced for PwD is predominantly available from online sources but PwD have limited ability and means to access the internet. The information covers a number of different aspects of design for dementia but no single source offers advice regarding all aspects. The books that offer the most complete advice are those which have to be purchased and therefore incur financial cost.

Although, simple written information may not offer the most effective medium with which to influence the lives of PwD, Healthcare professionals are limited by time, budget and service constraints which limits their accessibility.

These inconsistencies indicate an opportunity to investigate what impact the advice regarding home adaptation is having on PwD and their carers. It is not enough that the information and evidence is made available, if it is not utilised and engaged with. A clearer understanding of how the current information is being found and used in real domestic environments is much needed in order to guide future education provision.



### 3 Review of Literature: Health Behaviour Change Models

## 3.1 Health Behaviour Change Models

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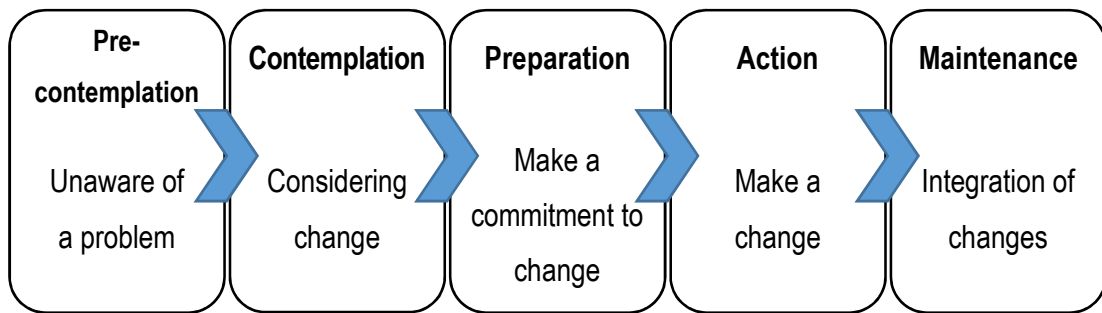
How decisions are made by individuals regarding the implementation of home adaptation can be explained with reference to health behaviour change models. Health behaviours are defined as activities undertaken by individuals in order to prevent ill health (Kasl and Cobb, 1966). Therefore the implementation of home adaptations which can influence the quality of life and prevent health crises such as falls can be classified as positive health behaviours.

Models of health behaviour and behaviour change models are used widely in the design of health interventions and programme planning (National Institute for Health and Care Excellence, 2007). These models both provide social-psychological perspectives relating to health behaviours and factors which influence them. However, the two types of models are distinct in purpose: Models of health behaviour describe factors that influence specific behaviours. Health behaviour change models attempt to describe how health behaviours change and can be influenced to change (Darnton, 2008).

Understanding the factors which influence individuals to accept or decline home adaptations, can improve services which support people living at home into old age such as Occupational Therapy, nursing and social care by creating targeted advice and support. If we take the literature on the attitudes of individuals towards and the implementation of home adaptation as a point of reference, we can explore complementary theories for health behaviour change and draw out key or common features.

### 3.1.1 Transtheoretical model of health behaviour change

The Transtheoretical Model of Health Behaviour Change (TMC) proposed by Prochaska and DiClemente, (1982) suggests that there are five stages to behaviour change for an individual. Pre-contemplation, Contemplation, Preparation, Action and Maintenance (Figure 4).



(Prochaska and DiClemente, 1982)

*Figure 4. Transtheoretical Model of Health Behaviour Change*

Individuals need to progress through each stage in turn in order to make long term changes to their health behaviour. However, unlike the Health Belief Model it is also possible to regress back through the stages if motivation or behaviour is not maintained.

### 3.1.1.1 Pre-contemplation

Developing an awareness of home adaptation and therefore passing beyond the pre-contemplation phase requires the receipt of information. Traditionally healthcare professionals have been the main source of home adaptation advice for older people (Mountain and Way, 2012). Access to appropriate healthcare professionals would require a referral triggered by an episode of ill health or social care breakdown. At this point patients would be assessed by therapists and given advice relating to a wide variety of home adaptations in order to assist with ADLs and prevent falls. In the UK most home adaptation advice is provided by OTs but may also be given by physiotherapists or nursing staff.

The model demonstrates that perceived conflict between health and social care professionals and clients may exist because the two parties are functioning at different stages of the model (Prochaska & DiClemente 1982). For example healthcare professionals can approach the assessment from the action stage as they have both previous experience and knowledge of home adaptations. This means that they are in a position to action the adaptations immediately. However, service users may still be at the pre-contemplation stage, where they have yet to perceive elements such as clutter as being a potential hazard. In the case of adaptations where the participants

have already experienced difficulties they start the process from the contemplation stage which means they only have to make the small step to the action stage. This could explain why some strategies appear more readily accepted than others (Prochaska and Velicer, 1997).

This hypothesis is further substantiated by Chee, Gitlin, Dennis, & Hauck, (2007) who found that carers participating in an environmental skill building program used more environmental strategies if they showed a higher level of readiness at the beginning of the trial. The study concludes that carers who have low levels of readiness may require initial information and teaching prior to the intervention in order to improve adherence and compliance (Chee *et al.*, 2007).

A descriptive study by Corcoran and Gitlin (2001) specifically concentrated on the acceptance of environmental modification strategies by family caregivers. The therapists in the study produced over one thousand different strategies to assist caregivers, averaging 119 per problem area. This was due to the individualisation of the plan for each patient and caregiver. Recommendations relating to changing tasks such as bathing and feeding (81%) more readily than those relating to objects such as removing clutter or using assistive technology (74%). It is unclear from the results whether the number of interventions offered affected the acceptance or uptake of these (Corcoran and Gitlin, 2001).

### **3.1.1.2 Contemplation**

Part of the process of contemplating change is the perception of both the risk of no action, and the possible benefits of change. With regards to changing the home environment there are also issues of design and the nature of the home. As found in the studies by Jonge *et al.* (2016) and Pettersson, Löfqvist and Malmgren Fänge, (2012) adaptations need to be aesthetically pleasing as well as functional (Section 2.7.1). Aesthetics are also positively linked to how much participants were willing to pay for equipment (Jonge *et al.*, 2016b). Therefore this has implications for moving through the preparation and action phases of the model.

#### **3.1.1.3 Preparation**

The preparation stage relates to an individual making a commitment to change, this means making plans for how the change will occur. Making plans regarding the financing of the adaptations or accepting the recommendation made by health and social care professionals.

The willingness to pay and financial considerations for home adaptations is discussed in Section 2.8. This stage is also influenced by whether the individual is in contact with a healthcare professional such as an OT who can arrange for home adaptations to take place.

#### **3.1.1.4 Action**

The ability of individuals to actually make changes to their home is influenced by who is responsible for the adaptations themselves. Adaptation of the home is most frequently triggered by an acute episode of illness rather than slow decline (Lansley *et al.*, 2005) and health and social care professionals such as Occupational Therapists, Physiotherapists, Nurses and Social Workers are the people most commonly responsible for assessing and ordering housing adaptations which can be made by in house equipment provision or 'handyman' services or tendered out to local trade services (Mountain and Way, 2012). Individuals can also decide to make changes themselves or arrange for them to be completed privately. This is influenced by finance as previously discussed (Section 2.7) and the ability of the individual to make or accept these arrangements.

#### **3.1.1.5 Maintenance**

How home adaptation changes are integrated into the homes and behaviours of older people and those with dementia relies on consistent use and is affected by changing abilities. As previously stated housing adaptation is rarely optimal and requires updating over time (Pettersson, Löfqvist and Malmgren Fänge, 2012) at least in part because of the changing abilities and functional capacity of the individual.

### 3.1.1.6 Augmented Transtheoretical Model

If we add the research evidence as factors that influence the stages of the Transtheoretical model an augmented model is produced in Figure 5.

The studies by Gerson et al (2005) and Kruse *et al.*, (2010) (Section 2.6.1) both focussed on the perceptions of home adaptations which were being advised but not yet made and found negative perceptions. Conversely studies by Niva and Skär, (2006) and Tanner, Tilse and de Jonge, (2008) interpreted the effects of previous housing modifications and found people had discovered renewed independence and control over their lives.

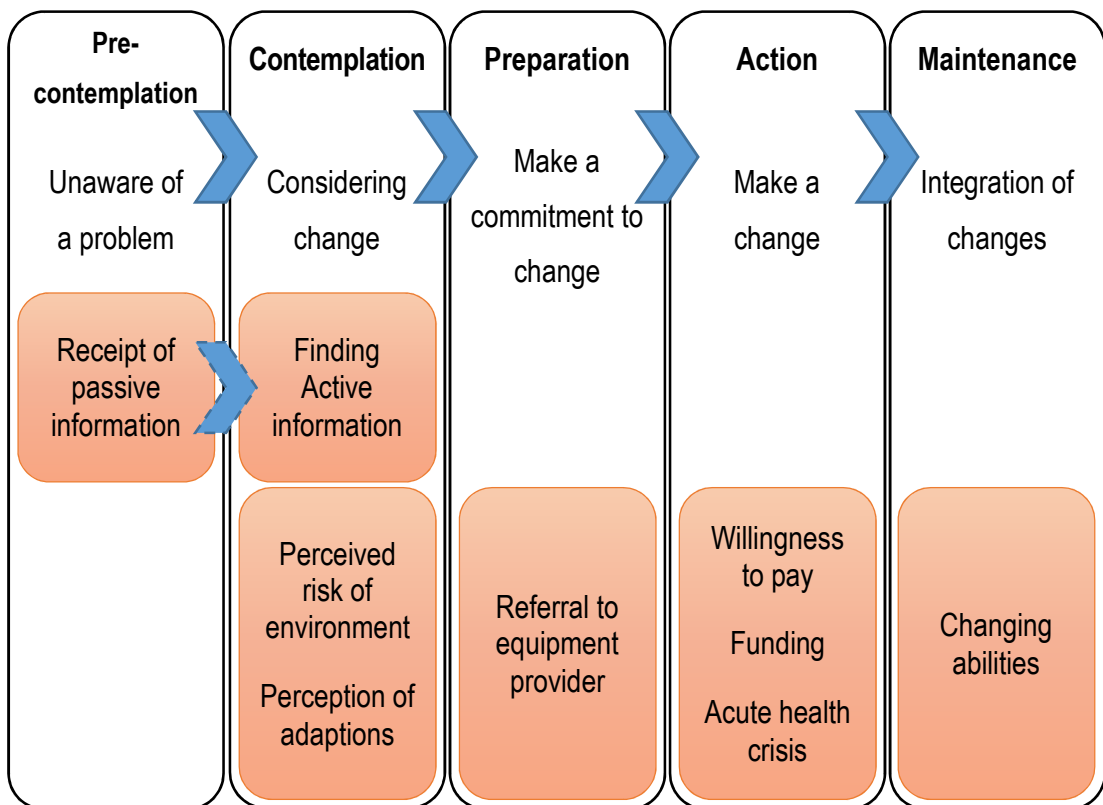


Figure 5. Augmented Transtheoretical model of health behaviour change

What is less clear from the model is the factors which influence how an individual passes from one stage to another. However the Health Belief Model (Rosenstock, 1974) provides further insights into these factors and their impact on the likelihood of change taking place. What the model does not show are the processes that lead an individual to progress from one stage to another. To begin to understand this, a further

health belief model is needed which connects health behaviour in relation to intrinsic and extrinsic factors.

### **3.1.2 Health Belief Model**

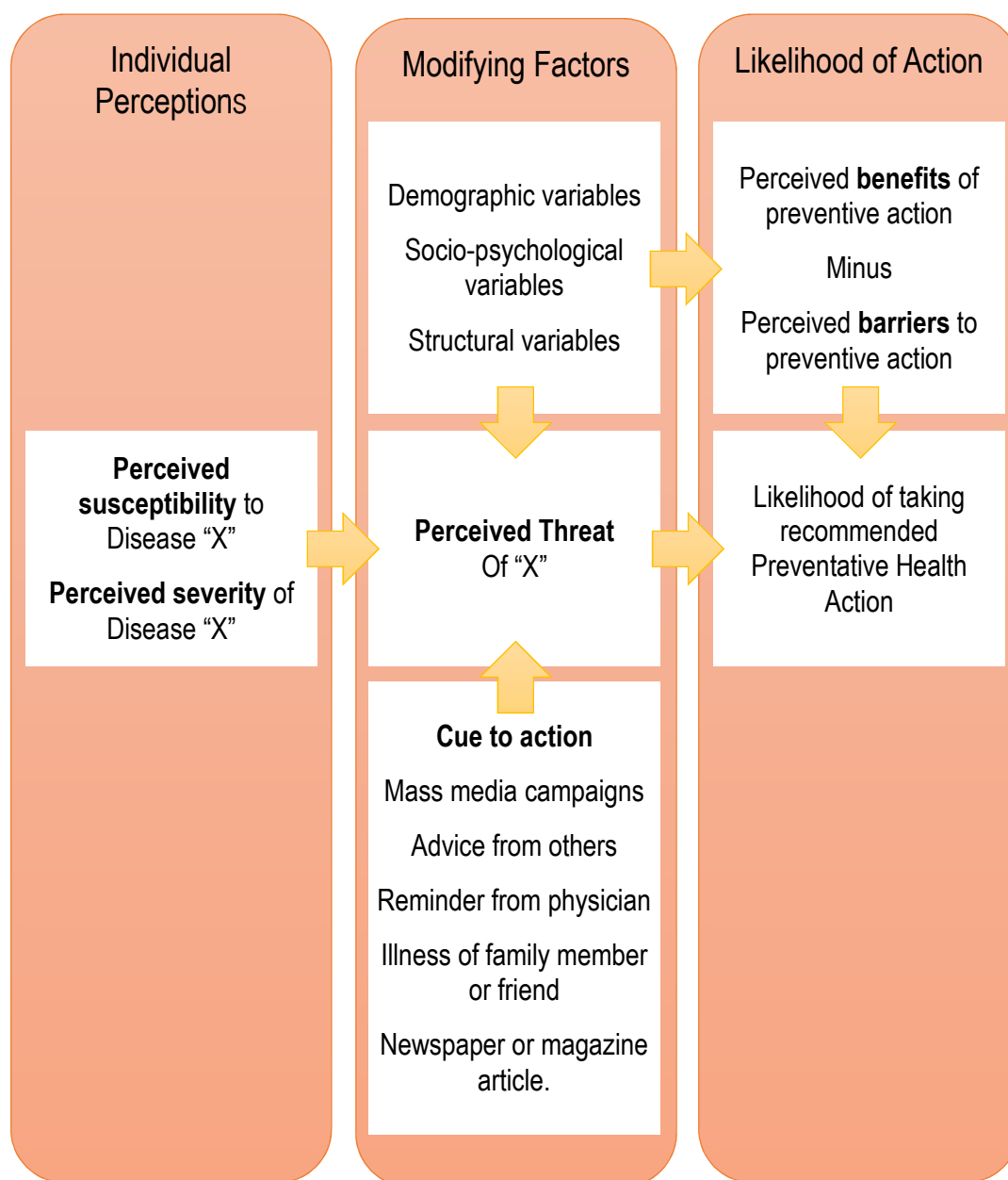
This model begins to explain the behaviour of those who have also taken on a sick-role. Sick-role behaviour is a type of health behaviour of people with health complaints in seeking out treatment and activities which will make them well (Becker, Drachman and Kirscht, 1974). The premises of the model can be separated into three areas, individual perceptions, modifying factors and likelihood of action

#### **3.1.2.1 Individual perceptions**

The internal perceptions contain two characteristics: Perceived susceptibility refers to perceived risk of being affected by a disease. Home adaptation does not mitigate the risk of disease but it can mitigate the risk of injury, for example risk of falling. Therefore a suitable concern here is the risk of injury rather than disease. Perceived severity relates to how severe the consequences of the condition are perceived to be, for example the risk of injury following a fall.

#### **3.1.2.2 Modifying Factors**

These are factors that can alter or modify an individual's perceived threat of a condition or situation. There are three different classifications of modifying factors: Demographic for example age and gender, Sociopsychological relating to personality and social class and finally structural which is associated with prior knowledge and experience of the disease. Both demographic and sociopsychological factors have been shown to affect the ability of an individual to be able to access and understand health related information, also known as health literacy (Johnson and Case, 2012). Health literacy is affected by a number of factors including age (Baker *et al.*, 2000), cognitive decline (Kaphingst *et al.*, 2014), education, social class and gender (Holman, 2015).



(Becker, M., Drachman, R., Kirscht, J., (1974) p206

*Figure 6. Health Belief Model*

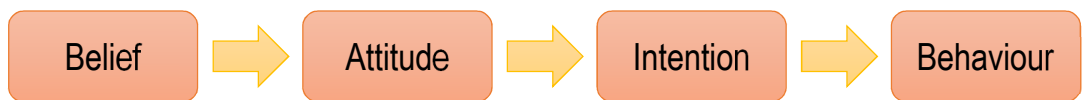
Structural which relates to previous experiences with the condition and knowledge. In home adaptation, past experience in home adaptation can also act as a cue to action. Awareness of potential problems within the environment and changes or equipment that has helped in previous situations can influence how soon action is taken.

Finally Cues to Action are those which prompt awareness or act as reminders. Active information searching is both a modifying factor and a type of action depending on the intended outcome.



### 3.1.2.3 Likelihood of Action

In this group there are two interconnected aspects. First the perceived barriers to an intervention are taken away from the perceived benefits, this then leads to the final likelihood of taking action which is also influenced by the perceived threat of the condition.



(Ajzen and Fishbein, 1980)

*Figure 7. Theory of Reasoned Action*

### 3.1.3 The Theory of Reasoned Action

The Theory of Reasoned Action also lends insight into the motivating factors of health beliefs and behaviours. Proposed by Ajzen & Fishbein, (1980) the theory states that behaviour is a product of intention which in turn is created by attitudes and beliefs (Figure 7). These beliefs and attitudes can influence decision making within early phases of the Implementation framework and more specifically influence the acceptance of objects such as, of living aids and equipment. Belief about objects can be positive or negative, people like objects that are seen as having positive attributes and dislike those with negative attributes. These feelings form salient beliefs which are those that are immediate and go on to form out attitudes towards an object. Ajzen and Fishbein state that in order to understand why people have certain attitudes towards an object it is necessary to understand what their salient beliefs are.

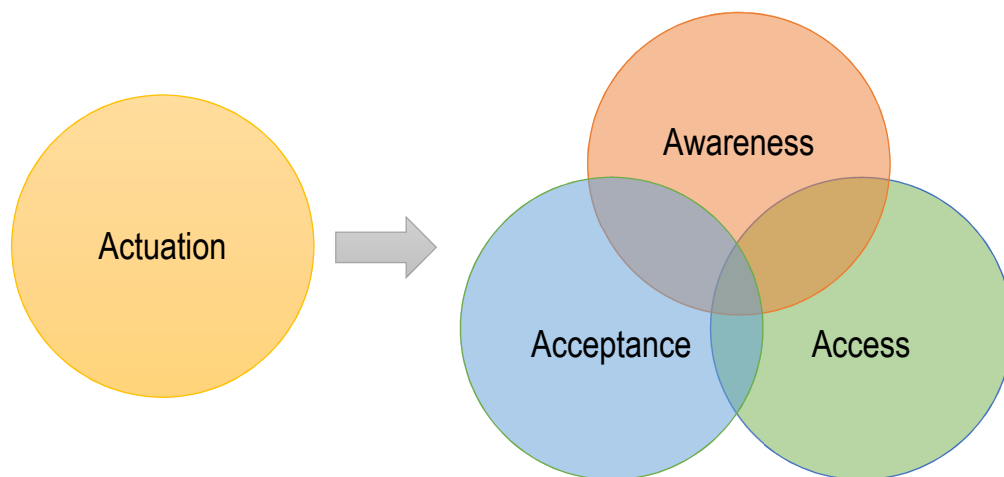
The failure of PwD and carers to accept some forms of equipment may be linked to negative salient beliefs towards these objects or advice which then cause the equipment to be dismissed within the contemplation phase. Findings by Heywood, (2005) lend weight to this. In interviews with people who underwent a series of home adaptations for a variety of long term conditions, they found that items such as commodes had negative connotations and this made them less desirable. The same too can be said for items which are perceived to resemble those in hospitals and

therefore detract from the home environment. The medical appearance of equipment was found to result in individuals putting off installing living aids until a crisis occurred (Powell *et al.*, 2017).

### 3.1.4 Home adaptation implementation framework

The current evidence shows that there are a number of factors which influence the uptake of, and attitudes towards adapting the home in old age. Acceptance of home adaptation by an individual begins with awareness created through either previous experience of similar issues which for example, could be linked to previous experience with an older relative or friend. Awareness may result from passive information obtained following a diagnosis of a condition or observed in mass media.

However, in the case of home adaptation for dementia, the awareness stage must be preceded by a trigger which leads to information specifically being sought or provided. This 'Actuation' phase (Figure 8) could be initiated through a diagnosis or onset of symptoms, or an acute health crisis, which then leads to contact with health professionals or personally activated information searches which then lead to an awareness of home adaptation concepts.



*Figure 8. Factors of influence over home adaptation implementation*

The influence of these factors can be explained (at least in part) when they are viewed alongside the discussed health behaviour change models (Figure 9). Whether an individual acts upon this information and awareness is dependent on internal factors

such as their perceived risk of future injury and understanding of the information presented. These factors themselves are influenced globally by the health literacy of the individual and their ability to understand the information that they have received. Health literacy is influenced by demographic factors such as age, gender and education.

Occupational Therapists have been shown to consider a number of aspects which influence the advice they give such as: Readiness for change, Compliance, Finances, Personal and social support, Logistical issues relating to the house (Stark L. *et al.*, 2015). These considerations are linked to all three aspects of the model. However other sources of health and social care support frequently address only one or two of the three aspects and which means an individual cannot pass along the whole of the behaviour change model and therefore, change does not occur.

### **3.1.5 Concluding thoughts on Health Behaviour change models and Home adaptation implementation**

The Transtheoretical model of health behaviour change sheds light on the stages that individuals must pass through in order to implement home adaptations, but do not identify the influences over moving along the continuum. These motivating factors are shown within the Health belief model and Theory of Reasoned Action. The resulting model can be simplified into four apparent aspects: actuation, awareness, acceptance and access which all need to be addressed before adaptation will physically occur in a home. However, it is not known which stages or factors hold the largest influence over the implementation of home adaptation in dementia.

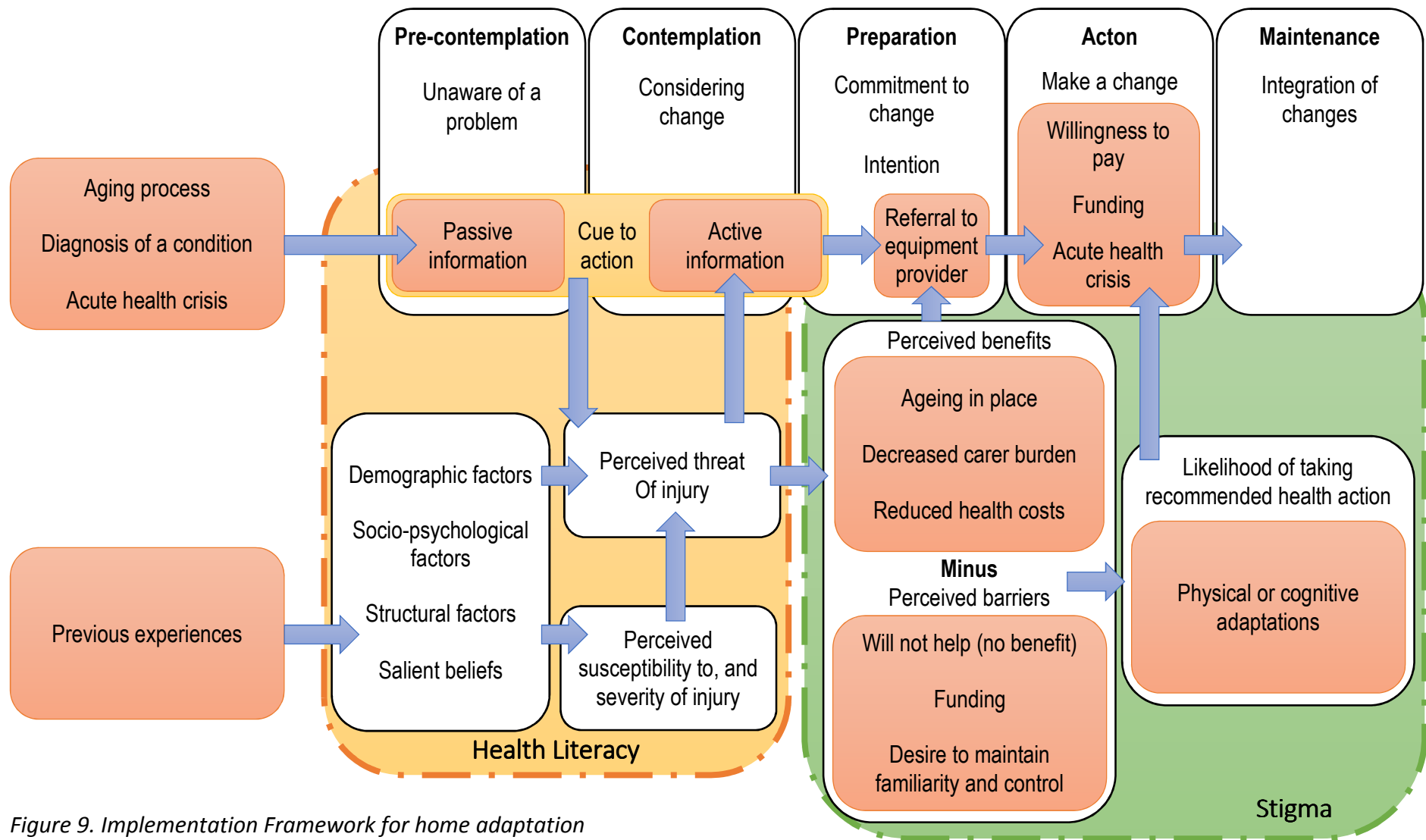


Figure 9. Implementation Framework for home adaptation

## 3.2 Literature Review Conclusion

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In Summary, evidence-based design has important implications for health and well-being which is important both within institutional settings and for domestic dwellings. Dementia is predominantly a disease of older age and affects how people interact with their home environment, a place where older people wish to remain throughout their lives. Research evidence suggests that there are many evidence-based home adaptations that can be made to a domestic dwelling, in order to improve the quality of life and function for people with dementia living at home.

Health behaviour change models show that the implementation of home adaptations for dementia may be affected by factors such as awareness, accessibility and perceived threat, but little is known about the actual influence of these factors on the uptake of home adaptation within the homes of people living in the community with dementia.

## 4 Methodology

## 4.1 Introduction

---

The purpose of the research described within this thesis is to widen the base of knowledge around home adaptation for dementia. This chapter outlines the methodological approach used to answer the research questions and gap in knowledge posed following the literature review. Due to a lack of previous research on the application of home adaptation for dementia in private dwellings, mixed methodologies were used to gain an increased understanding of the experiences, motivators and opinions of people with dementia, their close friends and family, along with practitioners who work with people with dementia.

### 4.1.1 Research Underpinning

The growing, global problem of dementia, as outlined in Chapter 1 means that there is a need to design products and services which truthfully meet the needs of PwD and those who care for them. The research here seeks to understand the real world knowledge and use of evidence based home adaption for dementia via the experiences of a variety of stakeholders, for example people living with dementia, their family and friends and health and social care professionals. Using these experiences it then goes on to seek the causal relationship behind the current use of adaptation within the homes of people with dementia. To achieve the objectives set out in Chapter 1 a sequential qualitative to quantitative design principle was used where data from each study was used to inform the design and enhance the performance of the next (Morgan, 2014). The initial study focussed on exploring experiences using purely qualitative interview data. The later studies use survey and case study responses (vignettes) to provide quantitative data in order to seek out the relationships between information source use, information provision and the use of home adaptation.

### 4.1.2 Research Paradigm

This research is concerned with how people living with dementia and their carers find and use information about home adaptation and the manner of response when faced

with advice based on published evidence. This is likely to be influenced by their previous life experiences and interactions. Individuals and populations have a wide variety of experiences that are tacit or unquantifiable in nature. However the social world cannot be discounted due to aspects of living with dementia such as social stigma and the need for PwD and their carers to be involved with health and social cares systems. Therefore a pragmatic paradigm was used which understands that knowledge of the world for the individual is based on their experience but that this experience takes place within a social world and consequently some of an individual's knowledge comes from a socially derived place. In this way research pragmatism falls between realism and constructivism (Morgan, 2014).

### **4.1.3 Research Structure**

The thesis consists of three distinct but connected studies, each investigating differing aspects of living with dementia and drawing on findings from previous research, including the other studies within the thesis itself. The structure of this and the objectives for each of the three component research studies are shown in Figure 10.



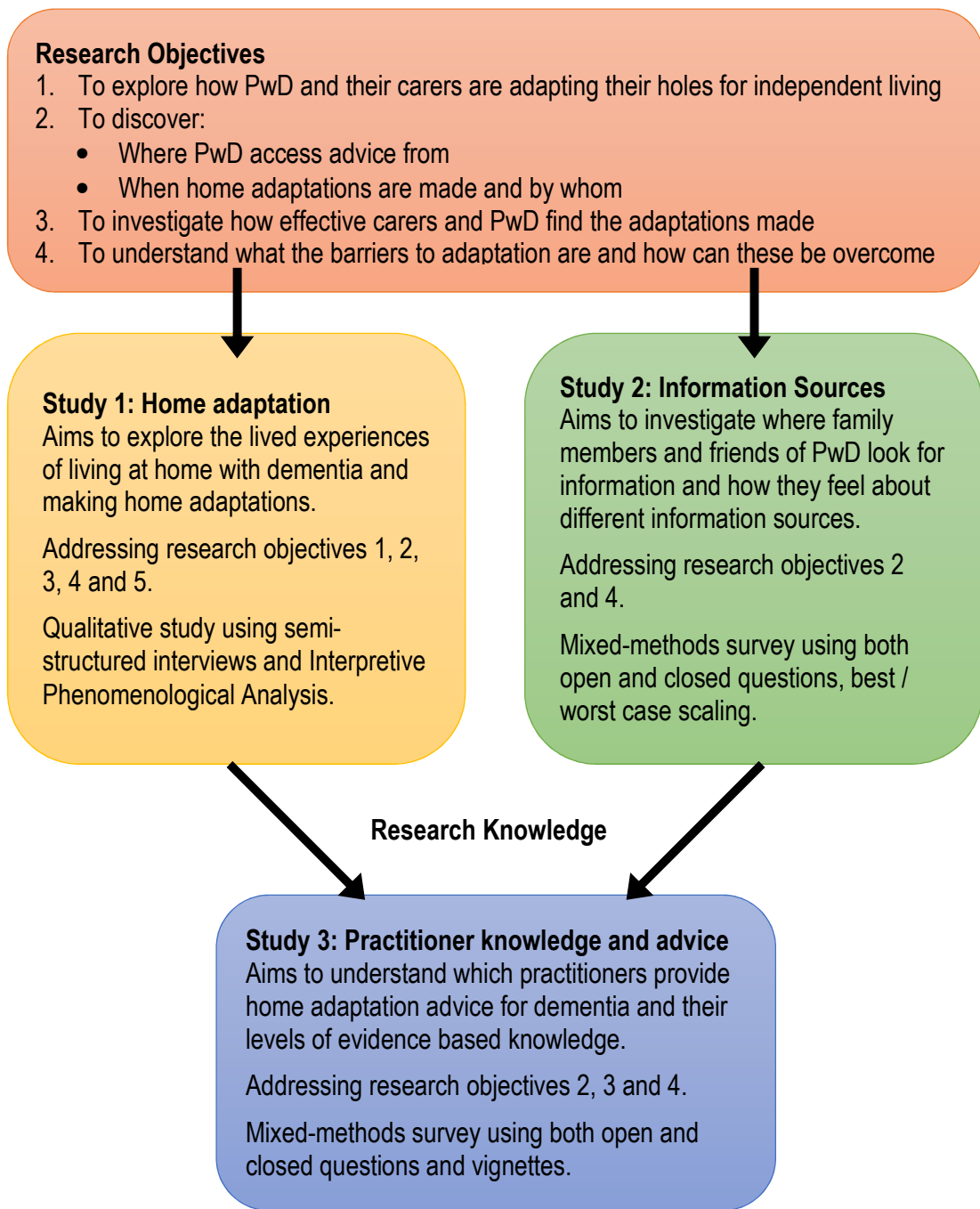


Figure 10. Research methods structure

#### 4.1.3.1 Validity

The structure demonstrates a triangulation of methods by beginning with qualitative data before moving to mixed and quantitative data (Roberts and Priest, 2010). The sequential approach to data collection that this represents means that the design of the survey data for the second and third studies were informed by the real life

experiences of PwD and their carers which added relevance to the questions (Morgan, 2014).

This type of triangulation of research methods aims to capture data that reflects a wide variety of standpoints and add validity to the data. Responses between study one and studies two and three are compared in order to add richness to the findings and develop a deeper understanding of the problem (Yin, 2014).

#### **4.1.3.2 Reliability**

In the context of research interviews, reliability is achieved through the accuracy of data collection (Roberts and Priest, 2010). Therefore, interview data was audio recorded and then transcribed verbatim by the researcher.

#### **4.1.3.3 Generalisability**

There are methodological restrictions of qualitative studies that in some ways limit the generalisability of the findings; low sample size and purposive sampling methods restrict how well the study can be applied to others. However, this research is specifically interested in the experiences of the participants and how these begin to answer the research questions. The methods of how data is collected and analysed are clearly described in order to allow independent appraisal of the generalisability to others.

#### **4.1.3.4 Scope**

The central objectives of the research form part of a design cycle, which begins with defining and understanding the problem that is to be overcome (Lewis and McNaughton Nicholls, 2013). The specifying of design needs is vital to the effective design of new products and services (Jack, 2013). It was not within the scope of this research project to design solutions to the issues found and therefore stops short of specification of attributes (Childs, 2014).

#### **4.1.4 Study 1: Home Adaptation**

Initially there was uncertainty from previous research as to the use of home adaptation in the lives of people living at home with dementia. Therefore a qualitative methodology was used to explore the personal experiences of those involved more deeply and therefore guide the ongoing research. This study utilised themes derived from phenomenology: the researcher undertook a bracketing exercise prior to data collection (Chapter 5), kept a reflexive diary and the interview data underwent a process of thematic analysis (Smith, Jonathan and Osborn, 2007). Semi-structured interviews were used to provide a guide to the themes discussed, whilst allowing participants to fully recount their experiences.

#### **4.1.5 Study 2: Information sources**

The second study required a larger investigation from a nationwide perspective to formulate ideas regarding the habits and opinions of people living with dementia. A survey methodology was used as this enabled a large amount of data to be collected in a timely way (Weissberg, Krosnick and Bowen, 2015). Open and closed responses were used to allow for breadth of information and to allow individual thoughts and feelings to be shared.

#### **4.1.6 Study 3: Practitioner knowledge and advice**

Following evidence from the first two studies, for the third and final study the research question was concerned with gauging the knowledge of practitioners working with PwD regarding home adaptation and how they pass on advice. Once again it was necessary to sample a wide variety of roles within health and social care and the Charity Sector therefore a survey based study was utilised.

For this study a vignette design was used in order to more accurately assess behaviour in clinical and professional situations. Vignettes are a type of artificial case study which allows participants to reflect on their knowledge and provide an insight into their own understanding and interpretation of a situation (Spalding and Phillips, 2007; Chiatti and Iwarsson, 2014). This was important for gathering data from health professionals

as closed questions were not likely to provide the breadth of professional choice and decision making used (Aviram, 2012).

#### **4.1.7 Characteristics of the sample**

The lives of PwD involve a complex network of formal and informal connections. This project has assessed the problems of home adaptation for dementia by including the experiences of people with dementia, their family members and friends, health and social care professionals and charities to attempt to form a holistic view of the use of evidence-based design in private dwellings.

For all studies, purposive sampling was used, which is defined as selecting participants who are most likely to be able to answer the research question (Roberts and Priest, 2010). As the focus of the research was related to the use of home adaptation for dementia within private dwellings it was necessary to recruit those who live at home rather than residential care or those without connection to people with dementia.

Recruitment for studies one and two was via the 'Join dementia research' (JDR) recruitment tool run by the National Institute for Health Research (NIHR). This is an online self-registration service that enables volunteers with memory problems or dementia, and their carers, to register their interest in taking part in research. The purpose of JDR is to allow volunteers to be identified by researchers as potentially eligible for their studies. Researchers are then able to contact volunteers, in line with the volunteer's preferred method of contact, to further discuss potential participation.

JDR is funded by the Department of Health, working in partnership with the charities Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. It is Health Research Authority (HRA) endorsed. The online service and all associated documentation, methods of contacting volunteers and handling of data provided by the NIHR, were reviewed by a specially convened HRA committee which included experts in research ethics, data protection and information governance. Formal endorsement was issued by the HRA on 20 May 2014 (National Institute for Health Research 2014).

For study 3, participants were required from a variety of both professional and charity practitioner roles. Once again purposive sampling was used to find respondents who had contact with people with dementia. Therefore, professional and charity groups were contacted directly and recruitment was through adverts placed online and in professional or charity publications. Snowball sampling was also utilised as those working within dementia care were encouraged to ask their colleagues to complete the survey.

#### 4.1.8 Ethical considerations for the use of PwD in research

To fully understand the lived reality of people living at home with dementia it was important to engage with PwD and those whom they live with. Using PwD in research means certain methodological and ethical considerations were made.

Historically people with cognitive impairment and communication difficulties including those with dementia have been largely excluded from research (Lloyd, Gatherer and Kalsy, 2006). Research into dementia has focussed on the biomedical model, thus concentrating on the disease process rather than taking a holistic view of the person (Cowdell, 2008). This research project aimed to consider and understand the lived experience of dementia, therefore it was vital to involve PwD in the initial study.

##### 4.1.8.1 Person centred research

The desire to conduct truly valid and person centred research for people living with dementia meant that the following factors formed the basis of a person centred methodology (McCormack, 2003; Dewing, 2007):

1. **Informed flexibility:** The researcher actively assists with decision making by providing information at the most appropriate time and uses a variety of approaches when talking about participating in research.
2. **Sympathetic presence:** Having an awareness of both verbal and non-verbal cues from participants to assist with decisions about participation.
3. **Negotiation:** Using the views of a participant to inform decision making about consent

4. **Mutuality:** Take time to understand the values of the participant and place these at the heart of decision making.
5. **Transparency:** Making the objectives of the research clear before collecting data.

Throughout the interview process it was important for the interviewer to acknowledge that answering questions in itself could make a participant with dementia feel threatened and anxious (Stalker, Gilliard and Downs, 1999). The risk of burden and negative emotional responses for participants was reduced by the interviews taking place within their own homes and by having the choice to have a close relative or friend present.

#### 4.1.8.2 Researcher Attributes

Following guidance from Keyes (2014) the researcher who conducted the interviews involving PwD maintained seven key attributes:

- Empathic
- Compassionate
- Knowledgeable
- Un-patronising
- Tolerant
- Respectful
- Understanding

(Keyes, 2014)

How these attributes were demonstrated, including the factors which were considered because they were likely to affect the participants with dementia, are shown in Table 6.

#### 4.1.8.3 Communication

Methodological considerations were also made with regard to communication techniques to assist with interviewing PwD by:

- Speaking clearly and facing the PwD, making sure their attention was engaged before beginning.
- Being patient in waiting for a reply as it often took longer for participants to respond.

- Not finishing sentences on behalf of participants if they had difficulties finding a word. When this occurred they were prompted or the question asked in a different way.
- When speech was hard to interpret, body language was noted and other knowledge about the person was used to guide understanding. Following this the meaning was always checked and no assumptions were made.
- External distraction was minimised, for example televisions and radios were switched off where possible.

(Barnes and Surr, 2010; McKeown *et al.*, 2010; Cantley, 2011; Keyes, 2014)

Adapting interview and communication techniques in this way assisted with the accuracy of the data collected and helped to avoid ambiguity in questions and replies.

Issues specific to using participants with dementia in qualitative research.	Researcher and Methodological considerations.
During an interview a participant may be taken outside their comfort zone (Keyes, 2014)	<p>The researcher took time to learn about the PwD from people who knew them well, and with whom they lived. In this way the researcher could assess signs of well-being during the interview process (Stalker, Gilliard and Downs, 1999; Keyes, 2014).</p> <p>Interviews took place at the participant's home and at a time of day to suit them.</p>
Consent and the ability to give consent can vary in dementia, and can change several times in just one session (West <i>et al.</i> , 2017).	<p>Both verbal and non-verbal communication were monitored by the researcher throughout the interview (Lloyd, Gatherer and Kalsy, 2006; Dewing, 2007).</p> <p>Researcher/interviewer kept clear notes of changes of consent and mood. Actions were described clearly and unambiguously.</p>
PwD may be more easily led in their answers.	<p>Interviewer used a reflex diary and bracketing exercise to prevent them imposing their own views on participants (Lloyd <i>et al.</i> 2006).</p> <p>Participants were given the option to have family members or a carer present. The researcher maintained an awareness that this could affect the validity of responses (Stalker <i>et al.</i> 1999).</p>
PwD may feel apprehensive about being interviewed.	<p>Time was designed into data collection appointments to put participants at ease. Beginning informally by talking about an aspect of their life such as family or garden before embarking on the interview itself (McKeown <i>et al.</i>, 2010).</p> <p>Meetings were concluded with a sense of achievement for the participant. Once again time was allowed to have a chat and details were left detailing how participants can get in touch following the interview if they so wish.</p>
PwD will fatigue more quickly than participants without dementia.	<p>Regular breaks were scheduled and offered if participants appeared to becoming fatigued or agitated.</p> <p>Appointments were kept to time and did not overrun.</p>
Cognitive impairment affects the ability to understand questions and information.	<p>Every attempt was made to keep questions unambiguous and logical. If the participant struggled to understand a question, it was phrased differently, the interview scheduled was kept flexible for this purpose (Barnes and Surr, 2010).</p> <p>The researcher was flexible in the wording which described the study, every effort was taken to explain using clear language that the participant could understand without being patronising (McKeown <i>et al.</i>, 2010; Keyes, 2014).</p>



	Consideration was given to avoid language which PwD may find offensive. Effort was taken to use supportive language. Jargon and acronyms were avoided.
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*Table 6. Considerations for the use of PwD in qualitative research*

#### 4.1.9 The importance of using PwD in research

There has recently been a move towards increased representation of PwD as participants in research. Historically people diagnosed with dementia were excluded and much research recruited a proxy to gather information. This has meant that the voice of PwD has been largely lost, which in itself has ethical implications (Cowdell, 2008; McKeown *et al.*, 2010).

Within the studies of this thesis, it was endeavoured to record the experiences of people with dementia. However this led to problems relating to obtaining ethical clearance for the second study. For example: Study 2 consisted of an online survey. Initially it was proposed to seek participants with dementia and/or their family and friends to participate. However, ethics reviewers were concerned about the quality of replies that may be received from PwD as the survey was to be completed remotely on the internet, thus not allowing for each respondent to have their capacity or ability to answer the questions formally assessed. Due to time constraints for the research it was decided to only include PwD if their family member or friend was also completing the survey. Challenges involving ethics committees and dementia research have also been acknowledged by previous researchers (Dewing, 2007; Cowdell, 2008; McKeown *et al.*, 2010)

What this indicates is a need for further clarification through research evidence of the ability of PwD to participate in research autonomously and through remote methods. Although this is an important recommendation for further work, the relative ability of PwD to participate fully in research is not addressed within this work.

#### 4.1.10 Conclusion

This chapter has considered the methods used within the research project and the special considerations needed to conduct research using PwD as participants. The initial qualitative study leads into two studies which include both qualitative and quantitative elements. The pragmatic structure assisted in the provision of richness to

the data and the rigour needed in quality research which defines the problems associated with the use of home adaptation in the dwellings of PwD.

## 5 The Use of Home Adaption by people living with Dementia

## 5.1 Introduction

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In order to begin to understand how home adaptation is being used and what this means to living at home with dementia, it was necessary to explore personal experiences from those with first-hand knowledge. This home adaptation study uses interviews to explore and comprehend the subjective experience of living at home with dementia.

### 5.1.1 Aims and Objectives

The aims of this study are to address Objective 1; to explore the lived experience for PwD and their carers in their own homes. The findings of the study aim to increase the depth of knowledge around how people adapt their living environments in light of a diagnosis of dementia.

Therefore the objectives of this study are:

1. To increase knowledge of the common challenges faced by people living with dementia and their carers at home by studying their real experiences.
2. To examine the different viewpoints of participants from a mix of dementia diagnoses and demographics.
3. To develop an insight into the current practical application of home adaptation in private residences.

### 5.1.2 Methodology

#### 5.1.2.1 Study type

This was a cross-sectional qualitative study using semi-structured interviews of PwD and their carers in their own home. This is appropriate to gain a subjective snapshot of the lives of people living at home with dementia and their carers and thus inform future research (Morgan, 2014).

### 5.1.2.2 Sampling

This exploratory study used purposive sampling from a voluntary register. Interpretive research relies on the analysis of qualitative data, in this case in-depth interviews. The Interpretive Phenomenological Analysis approach outlined by Smith & Osborn (2007) states that sample size should be kept small to allow for a penetrating depth of analysis of each participant and meaningful contrasts to be made between cases without researchers becoming overwhelmed by data. Analysis relied on the immersion of the researcher in the data to build a picture of the experiences of the participants. For these reasons, a small purposive sample of 10 participants was deemed appropriate.

### 5.1.2.3 Recruitment

As described in the Methodology (Chapter 4) recruitment was via the Join Dementia Research (JDR) recruitment tool run by the NIHR.

Prospective participants were identified by the JDR search tool based on:

- Geographic location limited to the West Midlands
- Indication that they either live with others or left this information blank
- Have a diagnosis of dementia

Individual records were then screened to establish whether individuals met the inclusion criteria. This was achieved by the screening of information on the JDR register and by contacting prospective participants via e-mail, post or phone as per their indicated preferences.

Once it was established that a participant met the inclusion criteria, they were then sent a copy of the Participant Information Leaflet (PIL) (Appendix A) via e-mail or post.

#### 5.1.2.3.1 Inclusion criteria

The inclusion criteria were broad in scope in order to allow a wide range of experiences to be explored:

- A person with diagnosis of dementia and their informal carer who live at the same address: The present study was interested in how dyads of PwD and their

carers adapt their lives at home and how dementia influences the meaning of home for this group.

- English speaker: Due to budget limitations of the study an interpreter was not practicable.
- Lives in domestic dwelling: The present study focussed specifically on issues related to living in a private residence.
- Have occupied the dwelling for at least 6 months: To establish that participants had been in the property long enough for adaptation to take place.
- Capacity to consent to participation in the study: It was deemed that under the Mental Capacity Act (The Stationary Office, 2007) there was insufficient justification to require individuals without capacity to participate.

#### *5.1.2.3.2 Exclusion criteria*

- Lives alone: As previously stated this study focussed on the lives of people who cohabit the same address, therefore PwD who live alone were excluded.
- Lacks capacity to consent to participation in the study: Individuals whose dementia had progressed so that they could not understand the meaning of the research or what it entailed, were excluded.

#### **5.1.2.4 Bracketing**

The phenomenological approach relies on the researcher acknowledging prior expectations and feelings that could bias their findings. Therefore prior to completing data collection interviews for the current study, a bracketing exercise was completed, (Appendix B). This exercise took the form of recording the preconceptions of the researcher according to aspects derived from previous professional experience, instinct and those derived from studying the literature. These were then documented and set aside.

#### **5.1.2.5 Reflexive diary**

Reflexivity of the researcher is an important feature within qualitative interview studies and it has been reported as best practice in the interviewing of PwD (Lloyd, Gatherer and Kalsy, 2006). A reflexive diary was kept by the researcher to note

thoughts and aspects of the interviews not documented on the audio recording. This assisted in the data collection by documenting how the researcher's thoughts and approach altered over time and how the researcher's prior experiences and expectations may have influenced their relationship with the participant and therefore the data collected.

#### **5.1.2.6 Objective ADL measures**

Although objective measures are available which are validated for measuring the competence of an individual in completing Activities of Daily Living (ADLs) as used by healthcare professionals and researchers (LN, Winter, MP, Hodgson, WW, *et al.*, 2010). For the purposes of this study, it was not deemed appropriate to add further time and concentration demands on the participants with dementia, especially given the length and in-depth nature of the interviews. Therefore, data collection was based exclusively on the qualitative experiences of the interviewees and their own perceived level of dementia.

#### **5.1.2.7 Data collection**

Semi-structured interviews mix open and closed questioning techniques to allowing for participants to elaborate on themes and talk freely about their experiences. An interview schedule (Appendix C) was written to provide cues for the interview but participants were allowed to talk and guide the interview according to their own experiences. This type of interview has been shown to be beneficial for phenomenological research (Roberts and Priest, 2010). The interviews concentrated on the home physical environment and how it has been changed since diagnosis of dementia. Both participants were present throughout the interview in order to provide insights and interaction from both. The views of both the PwD and their carer were audio recorded.

Each interview was conducted in the participant's home. Participant dyads consisted of a person with a diagnosis of dementia and a significant other who they lived with.



Information was gathered on a variety of topics, written as prompts within the interview schedule, a summary of which can be seen in Figure 11. The information gathering took place in one single meeting with the participants.

Demographic data	Advice and information	Feelings of home	Home adaptation	General
<ul style="list-style-type: none"> <li>• Age</li> <li>• Diagnosis</li> <li>• Time since diagnosis</li> <li>• Relationship</li> <li>• Time in current home</li> <li>• Symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• Types of advice</li> <li>• Who is involved</li> <li>• What has been helpful?</li> </ul>	<ul style="list-style-type: none"> <li>• Positives</li> <li>• Negatives</li> <li>• Future</li> <li>• History</li> <li>• Access</li> <li>• Importance of home</li> <li>• Community</li> </ul>	<ul style="list-style-type: none"> <li>• Added anything</li> <li>• Removed anything</li> <li>• Changed anything</li> <li>• Different rooms</li> <li>• Outside space</li> </ul>	<ul style="list-style-type: none"> <li>• Advice for others</li> <li>• Where do you go for advice?</li> </ul>

*Figure 11. Summary of interview schedule themes*

The interviews were conducted by a Health and Care Professions Council (HCPC) registered Allied Health Professional with experience of communicating with and obtaining information from PwD and their carer in their own home. Observation notes were taken by the interviewer in relation to the home adaptations discussed. Consent to take photographs of adaptations was sort from participants to allow for those that were difficult to describe, although in practice this was not needed.

Following the interview all participants were given information regarding how to access home adaptation and more general advice about dementia.

#### **5.1.2.8 Data analysis**

Interviews were transcribed verbatim from the audio recordings using NVIVO 10 software. The data were then coded and analysed using Interpretive Phenomenological Analysis (IPA) outlined by Smith & Osborn (2007). This method involves repeated reading of the interview transcripts and the abstraction of responses into recurrent themes which are then interpreted through successive analysis into meaning. NVIVI 10 software was used to compile codes and manage the data.

Interviews were all audio recorded following written consent of all participants. Written notes were also taken throughout the interviews which included notes on any behaviours or non-verbal communication demonstrated by participants. Word-for-word transcription of interviews was undertaken by the researcher as soon after the interview as was practicable and always within 1 week of completion. Transcription was completed manually by the researcher to encourage immersion in the data.

Following the initial data analysis, the coding and themes were reviewed by a second researcher in order to confirm the internal homogeneity and external heterogeneity of the themes. The second researcher also reviewed the transcripts from two interviews to establish whether all aspects of participant's responses were captured by the coding trees.

Each participant had the opportunity to review the transcript of their interview to confirm its accuracy but all declined.

### **5.1.3 Ethical Considerations**

#### **5.1.3.1 Informed consent**

All volunteers were provided with verbal information regarding what is involved via a telephone call to the carer prior to agreeing to participate. During the telephone call, information regarding the participant's usual routine, best time of day, and individual behaviours was established in order to reduce any stress and anxiety to the PwD at the time of the interview. This has been shown to aid the provision of consent by PwD and is an important part of person-centred research (Dewing, 2007; Keyes, 2014). At this time consent was sought to record the interview which was then confirmed again at the face-to-face interview.

If during the research process a participant lost capacity to consent, they were immediately withdrawn from the study. Any data collected up to the point of withdrawal was retained.

The use of non-verbal communication and body language is an important part of interviewing PwD (Cowdell, 2008), therefore, if at any time the participant with dementia displayed signs of anxiety or stress due to the research process a break was offered prior to proceeding with the interview. However, none of the participants accepted the offer of a break. This process was assisted by the presence of the carer who knew the participant with dementia and their behaviour patterns and ensured both participants were happy to continue.

A Participation Information Leaflet (PIL) and consent form was provided on meeting with the researcher who also described what participation in the study meant and signed consent was obtained at this time. A copy of the written consent form can be found in Appendix B. The PIL stated that participants could withdraw from the study at any time and contains contact information for the researcher for this purpose. See Appendix A.

#### **5.1.3.2 Participant Confidentiality**

All data were anonymised and not used in an identifiable way. At the point of transcription participant names were replaced with a single letter not linked to their real name. Any identifiable data mentioned in the interviews such as addresses or numbers were removed or anonymised during transcription.

#### **5.1.3.3 Data Security**

Demographic data was gathered by the interviewer relating to age, time since diagnosis, type of dementia and length of time in the home to provide background data for the study.

Collected physical data was kept in a locked filing cabinet, at the International Digital Laboratory at the University of Warwick. Electronic data was stored on a password protected computer in accordance with the data protection guidelines for the University of Warwick and the data protection act.

All data collected, consent forms, audio recordings, photographs and interview transcriptions are kept for ten years in accordance with University of Warwick policy.

#### **5.1.3.4 Lone working considerations**

Precautions were taken to ensure the safety of the researcher whilst attending participant's homes:

- A timetable of interviews and addresses was left in a locked drawer with a designated individual.
- The researcher carried a University of Warwick photo identity card and mobile phone at all times.
- Appointments were made during daylight hours.
- On arriving and leaving each property a message was sent to designated individual. If a message was not received at the expected time, the nominated person would try to contact the researcher. If contact could not be made in this way, the matter would have been escalated via a call to the police.

#### **5.1.3.5 Timescale**

Data collection took place between October and December 2015.

#### **5.1.3.6 Ethical Approval**

The study was approved by the NRES Committee Yorkshire & the Humber - Leeds West on 9<sup>th</sup> September 2015 on behalf of the Health Research Authority. NRES number 15/YH/0352.

## **5.2 Results**

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### **5.2.1 Study Participants**

Ten pairs of participants were recruited, as shown in dementia and Table 8. Participants with dementia two participants with dementia were unable to give informed consent on the day of the meeting, so an interview was conducted with the carer in both instances which enabled the inclusion of experiences of living at home and caring for someone at a more severe stage of the disease. All remaining dyads of participants opted to be interviewed together and all declined the opportunity to review the interview transcript. The interviews lasted between 20 and 90 minutes.

Interview	Participant	Age	Gender	Relationship to study partner
1	D	63	M	Partner
2	L	72	F	Spouse
3	M	66	F	Spouse
4	R	71	F	Spouse
5	W	52	F	Spouse
6	K	71	M	Spouse
7	G	68	F	Spouse
8	A	36	M	Son
9	B	50	F	Spouse
10	H	82	M	Spouse

*Table 7. Participants without dementia*

Participants with dementia had a mean age of 73.2 ( $\sigma=10.3$ ) and represented a range of different dementia diagnoses including Alzheimer's disease, Vascular, frontotemporal and dementia with Lewy bodies.

As shown in Table 7, the participant with dementia in interviews 5 and 9 are both classed as young onset dementia as they received their diagnosis before they had reached 60 years with participant F being diagnosed at aged fifty-one.

Not all study partners identify themselves as carers as they perceive that they do not yet perform any traditional caring tasks or that their role is part of normal married life. For the purposes of clarity, study partners without dementia are referred to as carers to make a clear demarcation between those with dementia and those without.

Interview	Participant	Age	Gender	Dementia type	Time since Diagnosis	Severity of symptoms (self-reported)
1	Unable to give consent	77	F	Alzheimer's	4 years	Severe
2	E	81	M	Alzheimer's & Vascular	18 months	Moderate
3	J	75	M	Unknown type	3 years	Mild
4	P	75	M	Alzheimer's	3 years	Mild

5	F	55	M	Frontotemporal	4 years	Moderate
6	A	72	F	Alzheimer's	2 months	Mild
7	C	76	M	Vascular	14 months	Mild
8	Unable to give consent	82	M	Vascular & Lewy body	18 months	Severe
9	S	55	M	Alzheimer's	9 months	Mild
10	T	84	F	Mixed	12 months	Mild

*Table 8. Participants with dementia*

Carers had a mean age of 61.3 ( $\sigma=13.4$ ). Participants lived in a variety of housing types, locations and for varying lengths of occupancy see **Error! Reference source not found..** Eleven participants were male and nine were female. There was diversity in gender for both participants with dementia and carers enabling different gender viewpoints for both roles.

#### 5.2.1.1 Types of Dwelling

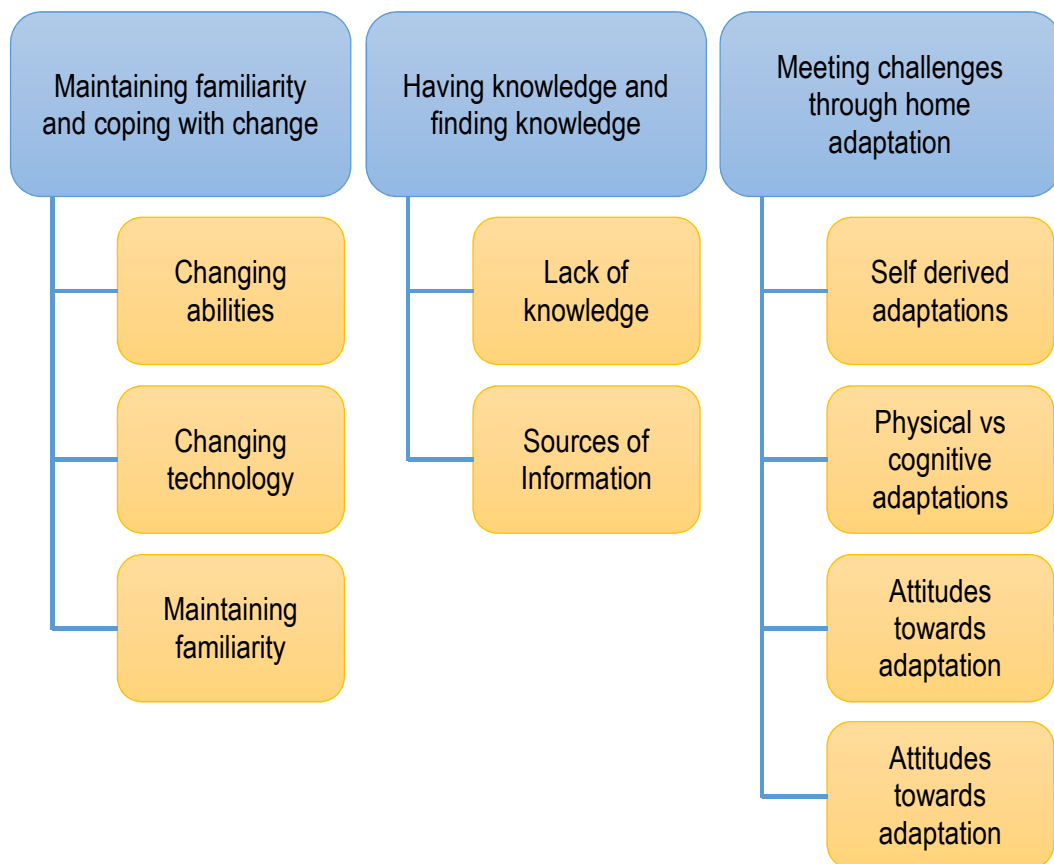
Whilst participants lived in a variety of dwelling as shown in Table 3, all were privately owned with none rented or owned by a third party. Three couples (5, 9 and 10) had moved house since the symptoms of dementia had started but only one (5) had moved house since diagnosis.

Interview	House type	Length of time at dwelling	Location
1	Semi detached	24 years	City, suburban
2	Detached house	32 years	Village, semi-rural
3	Detached house	28 years	Village, rural
4	Detached house	36 years	Village, cul de sac
5	Terraced house	17 months	City, urban
6	Detached house	44 years	Town, semi-rural
7	Detached house	36 years	Town, suburban
8	Terraced house	18 years	City, urban

9	Detached bungalow	2 years	Village, rural
10	Flat	3 years	Town, suburban

*Table 9. Types of housing occupied by participants*

The analysis of data identified three central themes: Maintaining familiarity and coping with change, having knowledge and finding knowledge, and meeting challenges through home adaptation. Nine sub-themes were then drawn from the central themes as shown in Figure 12.



*Figure 12. Themes drawn from the data*

### 5.2.2 Maintaining familiarity, coping with change

Participants expressed a variety of ways in which both PwD and carers respond to changes, some brought about by the changing nature of dementia and others through the changing nature of the world around them.

### 5.2.2.1 Changing abilities

Due to the progressive nature of dementia, the severity of symptoms experienced by participants is frequently changing and requires PwD and carers to make adaptations to solve new problems:

*“Up until this week...if I went into the bathroom to have a wash and a shave, J would come down on her own but since this... progression in her unsteadiness she’s not been allowed to come downstairs on her own. I keep the bedroom door locked” (Carer D)*

These adaptations made by participants were predominantly behavioural in nature, involving new ways to use the home or changes to a routine to work around new problems.

### 5.2.2.2 Changing technology

The majority of dyads had purchased or started to use new technology since the diagnosis of dementia had been given. For some, this adaptation had proved difficult to adapt to:

*“...cos obviously you have to have new phones you know when they go wrong and so we tried that and we've kind of given up on that haven't we, I just have to get used to the stress of knowing that I can't contact him or where he is.” (Carer B)*

Issues such as planned obsolescence mean that home technology and appliances frequently need replacing with new and potentially more complex items. New technology often led to using prompts or reminders in order to use effectively:

*“I did in the car like (use labels) because it's an electric (parking) brake and it's like underneath there's a little catch like that you pull on, push off and I couldn't get used to that. There are 'Pull on', 'Push off' little notes all over it”. (Participant with dementia J)*



In this example, a new technology was introduced that required adaptation of a long established skill (driving) and therefore had the potential to reduce the independence of the individual concerned which then led to an adaptation being made. Those at an earlier stage of dementia found that they were able to use new technology if given time to adapt: *"We had some new phones and he worked out how to use them quicker than me. ...He did it all by himself, I didn't tell him."* (Carer R). Therefore, these participants are able to adapt to some changes or make compromises to allow for difficulties in adapting to new technology.

### 5.2.2.3 Maintaining Familiarity

Participants stated that keeping familiarity in the home was important to them: *"...generally speaking he knows where the cereal bowls are kept, what bedroom we're in, in fact I feel I would confuse E by changing anything"* (Carer L). In contrast, three couples had completely redecorated their homes since the diagnosis of dementia. Changing décor was completed for aesthetic reasons and not with any consideration of how these changes could impact on dementia symptoms.

Five of the couples had considered moving house following the diagnosis but had concluded that they would prefer to age in place and make adjustments to their homes accordingly. A further four had never considered moving: *"We have thought about moving haven't we? But ... we had a stairlift put in and we got these chairs"* (Carer G)

This highlights attempts made by individuals to overcome environmental press by purchasing equipment designed to promote independence (Moore *et al.*, 2003) which is seen as a preferable outcome to moving house. One couple (interview 5) had moved house as a direct result of the diagnosis of dementia and a further two couples (interviews 9 and 10) had moved since their symptoms had begun. All three of these couples described difficulties in adapting to a residence but eventually settling well into their new environments:

*"I thought 'what have I done?' I wasn't prepared for it at all I just didn't know that this would happen, I thought I would bring F here and he would adjust like*

he did in his old house and I thought oh my goodness what have we done. It took him a while to adjust” (Carer W).

This demonstrates a lack of awareness as to the importance of a familiar environment for the symptoms of dementia but also highlights that PwD can adapt to a changing home environment, providing they have enough time to adjust.

For two couples, the importance of familiarity spread beyond the confines of their home into the community. A familiarity with people in the locality was a decisive factor in staying at home as participants feel supported by those around them. Having a supportive community assists carers to cope with the stresses of caring for a loved one with dementia and often provided practical as well as emotional support: “This is why we're not too keen to move because we've got a lot of support, everybody knows the situation so if C decides to go for a little walk, I sometimes get a phone-call you know. So it's very good” (Carer G).

Conversely, husband and wife in interview 10 decided to downsize because they were unable to cope with the demands of their original larger property. However they found changing to a different community setting and style of living environment formed a negative experience:

“Living in an apartment is so much much different than having your own, you've got to be so very careful and we have a lady above us and I think having been on her own she's listening out for everything...and she complained and the manager come and he went up and he listened and he said you couldn't hear a thing” (PwD T).

For this couple the effect of having immediate neighbours on all levels has made adapting to their new home difficult. They expressed that they felt they should have remained in their previous home and adapted to their new level of ability.

In summary, the changing nature of dementia means that people living with the condition are constantly adapting to new levels of ability. External changes, such as new technology also impact on functional levels and can cause increased impairment,

often in contradiction to the purposes of the new devices. Participants in the early stages describe a time of making wide spread changes to their living environment, however, those with moderate or severe symptoms protect the familiarity of the home by not making changes.

### 5.2.3 Having knowledge and finding knowledge

The overarching theme expressed by the participants was frustration at a perceived lack of general information about dementia and advice about how to live following diagnosis.

#### 5.2.3.1 Lack of knowledge

Out of the eighteen participants, only one (Carer G) had received information about how adapting the physical environment could alter symptoms of dementia. As Carer M says: *“I hadn't thought about it... It's interesting though I didn't know there was anything about that.”* (Carer M). However, although the topic had been covered in the carers support group that she attended, she was unable to recall specific detail. Over half the participants voiced frustration in trying to access appropriate and timely information about living with dementia:

*“When I got home after that (diagnosis)... I looked it up and I remember a day or two afterwards phoning my son and saying, I've got to tell the DVLA I think. Nobody had told me, it was on the internet... I did tell them at the memory clinic I said I think it's appalling that you just send people out, surely it's not beyond your wit to devise some kind of little information book”* (Carer R).

This participant emphasises the need for appropriate signposting of services and information and that people at different stages of dementia have differing needs. This view was also reflected by participants who felt that there lacked a clear source of information that meets their needs:

*“...we went to some of the Alzheimer's dementia cafes and you pick things up from there and you gradually thread your way through to find different things. But what everyone says, there needs to be, when you first start, a leaflet or a*

*book something that says this is where you can go, this is what you can access, this is what you can do. So you don't have to do it yourself” (Carer G).*

Participants were also concerned that when support and advice was offered it did not meet their needs specifically, this was highlighted by both of the couples affected by early onset dementia:

*“...things that are more appropriate to us you know like, benefits, you know cos I've had to stop work to care for S. ... I've only got 30 years of National Insurance Contributions so that's going to affect my pension so things like that... where they just tell you everywhere else ‘just to go to Citizens Advice’ you know, it's not ideal” (Carer B).*

This shows difficulties experienced when generic rather than individualised information is provided. Carer B then went on to explain their preference for face to face support and information which can be adjusted to answer specific questions.

Interestingly whilst participants expressed frustration at a lack of information about issues that affect them in the now, seven participants expressed a reluctance to access information about the future of living with dementia: *“I don't want to know about anything in the future. Cos then you would go mad” (Carer B).*

### **5.2.3.2 Sources of Information**

Participants used a wide variety of sources to collect dementia specific information including; support groups, support workers, healthcare professionals, the internet and mass media. Face to face meetings with dementia support workers were largely praised and a source of good information. There were mixed experiences of support groups with participants from interviews seven and ten valuing the peer support and information as vital. However, the majority of participants had negative feelings towards attending support groups: *“They were all doing the conga through the room. I could see his face and it sort of put him off completely” (Carer W).*

In this case the group activities clashed with the expectations of the participant. For others, attending a support group would mean mixing with those at a more advanced

stage of the disease which they felt they were not yet ready to face. This again represents a reluctance of participants to consider what their future may hold.

In the present study, none of the participants had looked for home adaptation information because they did not recognise that it is something that could affect cognitive or behavioural symptoms. Therefore, in order to be able to actively seek information, there needs to be either an understanding that there is information available on a subject, or the topic needs to be appropriately and clearly signposted from a main hub of information.

Mass media such as newspapers and television were also reported by four participants as a source of information about both managing symptoms of dementia and activities which act as a way of slowing the cognitive decline. They had then sought clarity regarding this from healthcare professionals. This shows that passive information has a role in highlighting areas that can then be actively sought at a later time:

*"I read things in the papers like they reckon cocoa helps so I think ok, have a bit of cocoa on your cereal in the morning and when you tell them at the memory clinic they laugh at you as if... he thinks I'm trying to do his job" (Carer R).*

Although seven of the carers reported using the internet to look for information about dementia, none of the PwD found information in this way. However, while the internet was used as an information source, it was seen as something which would provide too much information, and a negative outlook. *"I hold back a bit to look on the internet because sometimes a little knowledge is dangerous"* (Carer M). For others the over-reliance on the internet by health and social care workers was not helpful:

*"Cos I said if one more person tells me to go look it up on the internet, I will actually throw my laptop at them. You know, that's how bad it got, that's the only solution we were getting" (Carer B).*

All participants had been in contact with Dementia support workers from either health, social care or charity providers but the overwhelming majority could not recall receiving any information regarding home adaptation. Carer A had completed

extensive additive home adaptations and installed a variety of living aids to assist with personal care and mobility for his father. As an employee of social services, he was able to contact colleagues to gain advice, but felt that this information would be difficult for others to obtain. He goes on to explain that, even with a working knowledge of the social care system, it was difficult to obtain information and assessment of the home specific to his father's type of dementia:

*"I'm not sure if Alzheimer's Society or the dementia information support service, or the carers hub that we've got here, are clued up with the affects and the practicalities of dealing with a situation like this because they haven't been through it themselves" (Carer A).*

This points to issues regarding the perceived credibility in addition to the availability of the sources that are offering support.

In summary, there is a wide spread lack of home adaptation awareness and knowledge. This is part of wider problems with information provision following a diagnosis of dementia, where participants feel frustrated about not receiving essential information about the condition.

## 5.2.4 Meeting Challenges through home adaptation

### 5.2.4.1 Self-derived adaptations

The majority of the adaptations made were needs-driven and self-initiated, rather than as a result of provided information sources or a healthcare assessment:

*"I want to go to the shed to get a, a chisel or something, and by the time I unlock the door I've forgotten what I was looking for and this sort of thing. So to make life a little bit easier I have...different coloured buckets so I put my spanners in one and the other things in that so I sort of set things out." (Participant with dementia S).*

This participant shows that they have devised their own behavioural adaptation to overcome problems linked with memory and enabling them to reserve their role in

maintaining the home. In many cases, changes to the environment were made as a result of experiences in the home and through trial and error:

*“we realised we need this extra lighting...he steps out at night there's a light that lights up cos we've got a step and he's had a couple of tumbles there. So we've got a light there that comes on as soon as he steps out or if he walks down the garden to the garage”* (Carer W).

Lighting changes are an example of a transformative adaptation, here used as a physical tool to prevent falls.

#### **5.2.4.2 Physical vs Cognitive problems**

The most commonly completed adaptations made by participants were additive adaptations which address physical deficits and prevent falls such as grab-rails, and stair-lifts. For some, it was due to physical problems having a more immediate need (such as pain) or to aid moving around the home in order to be able to complete activities of daily living. *“The Occupational Therapist came (and) the level access shower had just been put in. She basically asked for another couple of grab rails for the shower area....”* (Carer A). The use of equipment to assist with cognitive symptoms was less well received. Carer B voiced concerns about the use of labels to assist with her husband's memory: *“I feel that's demeaning really (putting up signs). Don't get me wrong...I'd love to put signs all over the kitchen cupboards”* (Carer B). This demonstrates the need felt by carers to maintain home and adding labels is seen as detracting from the individuals' place within their home.

#### **5.2.4.3 Scale of changes**

For participants in the earlier stages of dementia, the adaptations that had been made were small in scale and highlighted the significance of outwardly trivial issues. *“...this carpet, could do with a good vacuum,... with things left on the floor, those dog toys or a pattern ... that can cause me to get confused and then down I go”* (Participant with dementia C). In this example, participant C describes the importance of keeping the floor clean to avoid the perceptual disturbances caused by objects or patterns on the

floor. This is an example of a simple subtractive adaptation (Pynoos et al., 2012) which was described by three participants as a method they use to prevent falls.

Small additive adaptations were also made: *"he doesn't remember which toothbrush is his, cos we've got this thing with the three toothbrushes in so on F's toothbrush he has either a piece of ribbon or a sticker so he can see which one is his"* (Carer W). This example of simple colour labelling means that Participant 'F' can continue to clean his teeth independently.

#### **5.2.4.4 Attitudes towards adaptations**

Participants in the current study voiced a positive attitude towards equipment that would meet physical needs and that any equipment would be considered if they saw a need:

*"...you have to be practical, if there is problems you overcome them, where you can. There's always a solution, and (if) the solution is put the bed down there and that's where it will go"* (Carer D).

Participants voiced a willingness to make appropriate changes to their home in order for it to continue to meet their needs. *"...if one of us is in a wheelchair we'll have to have a ramp I suppose"* (Carer R). One participant also stated that they would consider adaptations as the need arose *"... think we have things as we need them, you know you think of something that we might need but we're more than likely to go out and get it ourselves"* (Carer G), but here Carer G indicates that they would want to remain autonomous in their choice of equipment.

In summary, adaptation to the physical home environment were predominantly small scale, self-derived additive changes which were initiated by necessity or perceived problems. Participants were outwardly positive towards the concept of home adaptation but spoke about changes in the future tense, rather than something that they are considering at the current time.



### 5.2.5 Discussion

The aims of this study were to increase the depth of knowledge around how people adapt their living environments in light of a diagnosis of dementia and whether evidence regarding improved physical environments is having an impact on their lives. The results highlighted an absence of home adaptation in the homes of people with dementia. Although participants described home adaptations which arise from all four classifications of adaptations: transformative, behavioural, additive and subtractive as described by Pynoos *et al.* (2012), changes remain small in scale. In agreement with the previous research e.g. Marquardt *et al.* (2011), the most common group of adaptations were additive with additions of grab rails, furniture and security measures being made. Transformative changes such as moving furniture, were less well used, though it is notable that no participants had changed flooring, wall colour or, daytime lighting or added signs in order to aid dementia symptoms. For example, Carers had not opted to use concepts which could reduce carer burden and improve the independence of those they care for (Pollock and Fuggle, 2013). The main barriers to the use of home adaptation were: a lack of knowledge about home adaptation, attempts to maintain familiarity at home and perceived lack of credibility of sources of advice.

The participants described frustration at their reduced competence to complete previously straightforward tasks around the home and feel a corresponding loss of control and dependency on their loved ones. These experiences are in agreement with previous qualitative research by Steeman *et al.* (2006). Home adaptation research has provided evidence that the loss of independence and control can be mitigated by modifying the environment, indeed it has been shown that making home adaptations before they are specifically required can delay admission to long term care and prevent hospital admissions (Eriksen, Greenhalgh-Stanley and Engelhardt, 2015).

Although participants found maintaining a familiar environment was key (in agreement with Marquardt *et al.*, 2011; Damme and Ray-Degges, 2016), their experiences show that PwD are constantly adapting to change at home due to the progressive nature of dementia, changing technology and environments. PwD were

able to adapt to new environments and equipment if given enough time to do so. Consequently it is hypothesised that adopting change at the right time could be the most significant factor when considering adapting the home. This indicates that individuals may benefit from targeted, individualised home adaptation advice nearer diagnosis. This would mean home adaptation concepts could be considered when people make other routine alterations to their home and whilst they maintain the ability to adapt to the changes.

The desire to maintain what is familiar is also a way of preserving normality and maintaining identity for PwD (von Kutzleben *et al.*, 2012). This may explain the participants using of phrases such as 'have to' or 'need to' in the response to questions about feelings towards equipment. Participants largely voiced positive feelings towards home adaptations which is in contrast to the findings from previous research studies (Kruse *et al.*, 2010; Marquardt *et al.*, 2011; Damme and Ray-Degges, 2016). The main reason given in the previous studies for declining equipment or adaptations was that the changes were not needed (Kruse *et al.*, 2010; Marquardt *et al.*, 2011). Terms used here such as 'need to' imply that whilst seen as helpful, equipment will be considered only if they are unable to cope without it, a point which is unseen and in the future. Further investigation is needed to ascertain how making modifications to the home nearer to diagnosis could impact on the personhood and feelings of normality for the people who live there and whether making earlier adaptation can influence the independence and lived experiences for PwD and their carers in the long term.

This leads to a further explanation as to why home adaptation has not been considered by the participants here, which is the propensity not to think about the future. Proactively making changes to the home requires them to come to terms with their future needs, and therefore has not been discovered as a way of meeting their current needs. The majority of the current participants were in the mild to moderate levels of dementia which means they may still be coming to terms with the dementia diagnosis and therefore are not yet be ready to recognise and utilise the help and information that is available as posited by Boots *et al.*, (2015). What remains unclear is whether

improved information regarding how the home environment can enhance independence could bring it into the repository of knowledge that PwD and their carers use to cope with the present.

There is potential for much dementia care information to be received passively if it is not provided at a time where the information responds to an individual need. In this way individuals might not be able to utilise it effectively (Boots *et al.*, 2015). The only participant who had heard of home adaptation in dementia may not have been able to recall the details of the advice, as she had received the information passively from a support group speaker. This supports evidence which suggests that information should be personalised (Harland and Bath, 2008; Washington *et al.*, 2011; Johnson and Case, 2012) which understands that responses to information are affected by the context and prior experiences of the individual.

The findings presented here shows that it is the lack of knowledge of how the physical environment can specifically support PwD that represents the most significant barrier to making home adaptations. This demonstrates that home adaptation advice offered by the currently available sources is not being effectively received by PwD and their carers. Additionally, a lack of perceived credibility may account for why individuals do not use dementia advice (Sweet *et al.*, 2013). This causes a breakdown in the information pathway between home adaptation advice being made available and its translation into modifications in the homes of PwD.

In order to be able to actively seek information, there needs to be either an understanding that there is information available on a subject, or the topic needs to be appropriately and clearly signposted from a main hub of information. For example, in the present study, none of the participants had looked for home adaptation information because they did not recognise that it was something that could have an effect on cognitive or behavioural symptoms.

In agreement with previous research, the adaptations which were most likely to be used were those to address physical limitations rather than those shown to improve cognitive or behavioural symptoms (Marquardt *et al.*, 2011; Gabriel, Faulkner and

Stirling, 2015; Damme and Ray-Degges, 2016). For example, lighting was changed to prevent mechanical falls rather than augmented to improve sleep and behaviour patterns (Torrington and Tregenza, 2007).

Interestingly, information seeking behaviour studies have concluded that carers of PwD request information regarding the management of behavioural symptoms rather than mobility problems (Koenig, Steiner and Pierce, 2011). Hence there appears to be a disparity between the desire to learn ways of managing behavioural problems and the use of home adaptation, which has been shown to reduce some behavioural symptoms in dementia.

Alternatively this could indicate that dementia support workers for these participants are not offering information regarding how home adaptation can affect dementia symptoms. This may be due to the large amount of information they are required to present in relatively small time periods or that there is a lack of awareness regarding home adaptation within dementia support workers.

Any home adaptations that were used by participants were self-derived, therefore it is possible that adaptations for physical impairments are more logical to adopt without prior knowledge and consequently are a more easily determined solution. It is also conceivable that adaptations that address common physical problems present less stigma than those which aid cognitive impairments, therefore these are more readily accepted (Brodaty *et al.*, 2005).

The most significant finding of the study is shown in Figure 12, a potential framework for the application of home adaptation following a diagnosis of dementia. A lack of information and support following diagnosis means that changes are made to the home physical environment but not in relation to future needs and then as dementia symptoms increase maintaining familiarity becomes the overriding concern so changing the home environment becomes more difficult. This means that changes are then only made in the face of physical need or to be able to return home from an acute care setting.

This shows that the most effective window of time for the introduction of home adaptations to assist with dementia symptoms is missed due to a lack of awareness. Furthermore this Optimal Home Adaptation Phase (OHAP) also coincides to a time when PwD and those with whom they live are making substantial changes to their living environments but not necessarily changes that can aid their condition.

Defining the OHAP is important because by understanding that this phase exists, services and information can target specific home adaptation information for PwD in this phase. This means that when PwD make any changes to their homes following their diagnosis, they are able to consider the most effective way to implement these to achieve future benefit from their home environment.

The data here shows that information about home adaptation for dementia is not reaching people in the OHAP, despite being readily available. This means that those newly diagnosed with dementia or their carers are not finding or receiving the information, however, the reasons for this remain unclear.

#### **5.2.5.1 Limitations to the present study**

Whilst stringent efforts were made to remove bias and inconsistency from the research methodology, there are ways in which future research could improve on the methods used here. Including PwD in the participant dyads meant that only those with mild to moderate symptoms could be recruited. As dementia is progressive in nature it is likely that strategies such as home adaptation may become more prevalent during more advanced stages of the disease.

Due to time and budget constraints, sampling was limited to people from the West Midlands region (United Kingdom) and whilst participants resided in several different NHS trust localities, it is unlikely that their healthcare experiences can be generalised to the wider population.

Participant dyads were given the option to be interviewed together or separately, and all chose to be interviewed together. This may have led to participants withholding

experiences or views that the other participant may find distressing and therefore not providing a comprehensive review of their personal experiences.

As stated in the methods section, it was deemed too strenuous for participants to undertake extended involvement or repeated research visits to take objective outcome measures for their functional ability within the home. However, it is noted that if objective measures of functional ability within the home were taken, then these could have been used to compare the experiences between participants and whether these differences led to differing attachments and changes made to their homes. This mixed-methods approach would add depth to the data and analysis.

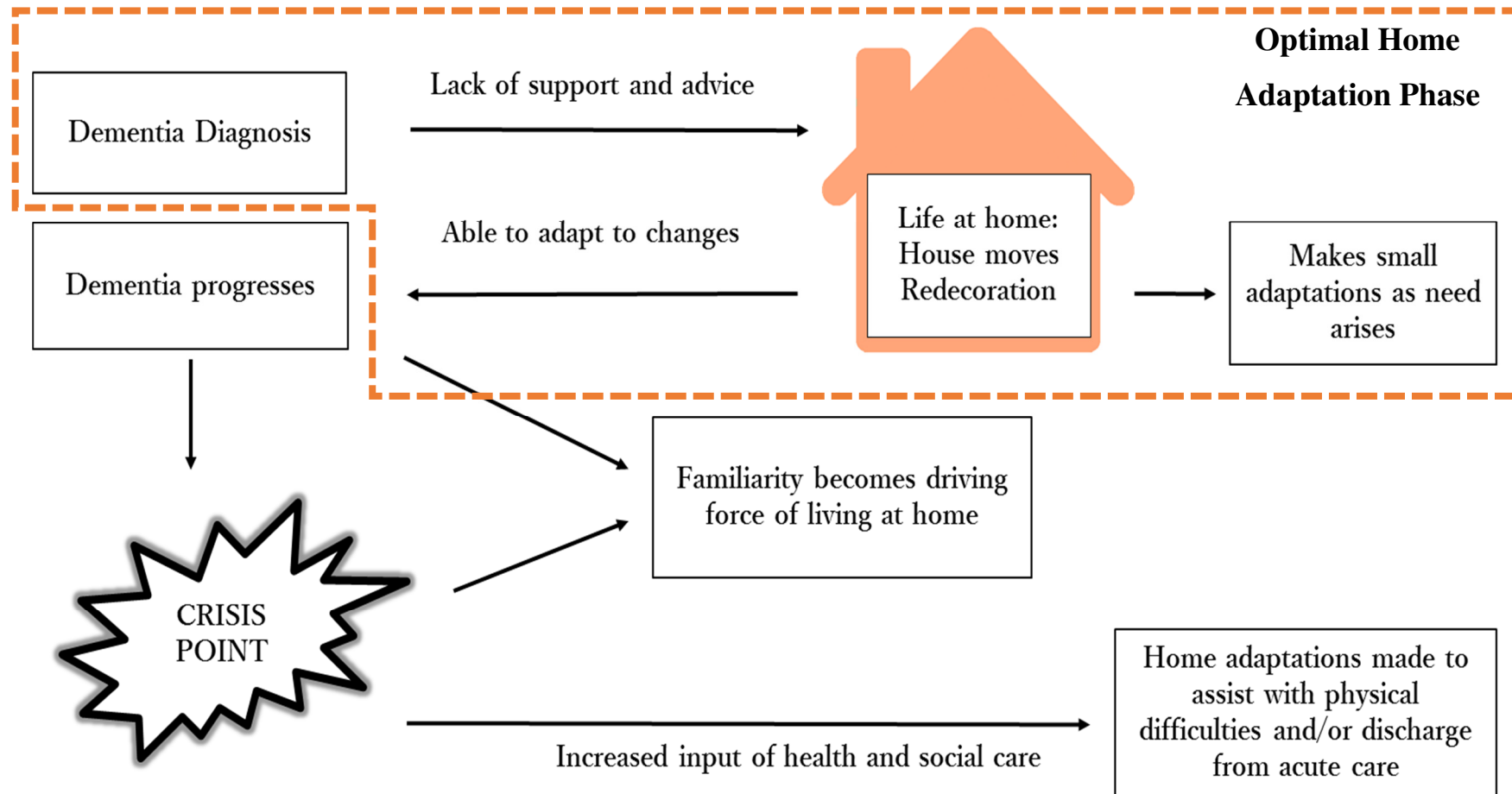


Figure 13. Explanatory framework of home adaptation following a dementia diagnosis

## 5.3 Conclusions

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Participants living with dementia are making small changes to their living space following diagnosis to address challenges created by dementia, predominantly these changes are to address physical limitations. The adaptations utilised by participants are largely self-derived and not influenced by home adaptation advice or literature. Where difficulties exist that could be mitigated through the use of home adaptation, individuals do not consider them as a possibility due to a lack of awareness or through a desire to maintain the status quo within the home.

In disagreement with previous research, PwD are able to adjust to major changes within the home environment such as redecorating or moving house, providing these changes are made soon after diagnosis and before dementia symptoms deteriorate. This indicates that there is an Optimum Home Adaptation Phase, which could be utilised in order to increase the uptake of home adaptation in domestic dwellings.

Barriers to adapting the home within the optimum phase exist due to a breakdown in the pathway between evidence produced by research, advice dissemination by charities and health care groups, and then being transformed into physical changes in the home. The reported experiences indicate that this breakdown may be part of a more substantial problem: a lack of appropriate, individualised and credible information and support available to PwD and their carers following a diagnosis of dementia.

Evidence shows that home adaptation can assist in keeping PwD living at home for longer, and lessen the burden felt by their carers. However there is a need to explore how home adaptation can be better promoted to make it more easily accessible and readily utilised by this population. Furthermore, are there ways to introduce home adaptations to address behavioural and cognitive symptoms which can make them more useable to PwD and their carers?



### 5.3.1 Next Steps

The evidence from Study 1: Home adaptation indicated that the potential impact from the design of the home environment was largely unknown by people living at home with dementia. Therefore further exploration of the aesthetic design of home adaptations was not indicated at this point. Initially it was important to discover where the breakdown in provision of evidence based home adaptation lies.

In order to discover why evidence-based home adaptation information is disseminated on a variety of platforms (Table 4) but not received by PwD and those close to them, a second study was undertaken to discover where and how this population seek health information.

Models shown in Chapter 3, show that in order to initiate a health behaviour change there needs to be a cue to action, which is through receiving information from a variety of different sources (Becker, Drachman and Kirscht, 1974). This will explore how they feel about different information sources and how they feel about the information provided. By investigating health information seeking habits, it is hoped to discover why home adaptation advice is missed or not acted upon.

## 6 Dementia Information Sources: Review of the Literature

## 6.1 Introduction

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This chapter describes a literature review which follows the previous home adaptation study described in Chapter 5. A further literature review was undertaken following the findings of the home adaptation study (Chapter 5), this was because a lack of information and knowledge of home adaptation was found to be a cause of the poor uptake of home adaptation within the homes of PwD and their close friends or relatives. Therefore, it was necessary to understand the previous research evidence linked to health information provision and seeking and factors which affect this.

As previously stated, information on home adaptation for PwD is available from multiple sources, however evidence from Chapter 5, shows that People living at home with dementia and their carers were not using home adaptation due to a lack of knowledge that home adaptation could influence dementia symptoms and independence at home. Therefore, there is a breakdown in the information pathway. The NICE Quality Standards for support in health and social care in dementia state that people who are newly diagnosed with dementia should receive both written and verbal information about their, treatment options, condition and services that are available in the locality (National Institute for Health and Care Excellence, 2010).

Information seeking has been shown to be used by caregivers as a form of coping strategy and as a way of maintaining control following a diagnosis of dementia (Boots *et al.*, 2015). Indeed, there are a number of different information channels available to those seeking health information. Traditional sources such as health and social care professionals, newspapers and printed media are now used in conjunction with more modern methods such as the internet and social media (Anderson, Nikzad-Terhune and Gaugler, 2009; Sweet *et al.*, 2013; Altizer *et al.*, 2014).

Family members frequently seek information, both, to aid them in coming to terms with a diagnosis and to act as a liaison between the information and the person whom they look after (Johnson & Case, 2012). An information source is a repository that is both a store and a provider of knowledge (Zimmer, Henry and Butler, 2007). Despite the number of different information sources available, PwD and their carers have been

shown to feel that they are not as well informed about the condition as they would like (Washington *et al.*, 2011; Allen, Cain and Meyer, 2017).

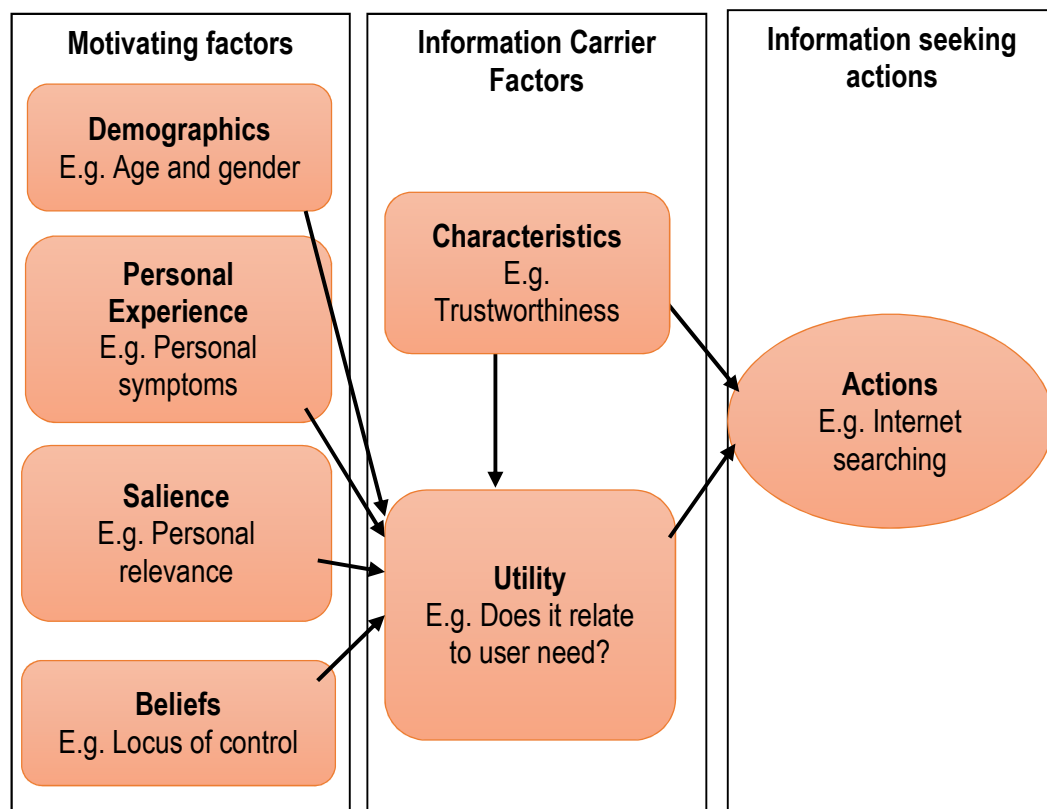
When considering ways of receiving information there are two overarching paradigms: System-centred and User-centred which are based on contrasting beliefs about how individuals react to information sources. Historically, health information has been viewed as existing in the system-centred paradigm which sees the information user as a passive consumer (Harland and Bath, 2008). If the information is provided in the same way it will have the same effect on the end user. Therefore, recommendations relating to information provision within the system-centred paradigm concentrated on the methods of delivery (Harland and Bath, 2008). For example, Wald *et al.* (2003) proposed that dementia caregivers should be given disease related information by health professionals using the 'Rule of three' approach. This model proposes that patients should be given three categories of information at a time and goes on to prescribe which topics should be discussed and when (Wald *et al.*, 2003). However, the researchers do not describe how the concept of the three topics was derived and this technique does not take into account the preferences of the individual.

The alternative User-centred paradigm focusses on the individual as a user of information and understands that the user's perception of the information is unique and dynamic. Under this paradigm, information needs to be adaptable to individual need. Working within the User-centred paradigm, the Comprehensive Model of Information Seeking (CMIS) was devised by Johnson & Meischke (1993) to describe factors that affect information seeking in cancer patients. It has since been successfully used to evaluate how information is used in wider populations (Sweet *et al.*, 2013). The CMIS acknowledges that responding to information is an active process which is influenced by the antecedents and previous experiences of an individual and therefore is unique to each person. However, the framework also states that Carrier Factors such as credibility and trustworthiness also affect how a source may be utilised (Johnson & Meischke 1993; Johnson & Case, 2012)

Sweet et al. (2013) used the CMIS as a framework to investigate how people with Multiple Sclerosis (MS) look for information regarding physical activity. The information gathered from focus groups (n=7) and telephone interviews (n=14) found that participants expressed an interest in exercise information, however they were more likely to engage with the information if it was clearly specific to certain symptoms and relevant to them. Information from health professionals was seen as credible but difficult to obtain and conversely the internet yielded information that was easily accessible but often lacks trustworthiness. The exception to this was MS society (Canada) website which was seen as a credible source (Sweet *et al.*, 2013).

Participants in the MS study also highlighted that their ability to utilise information was increased if provided at the right time. Likewise dementia research has found timeliness important; focus groups conducted by Robinson et al. (2009) with family carers of PwD (n=15) explored their experiences accessing information and services in Australia. They concluded that for caregivers the ability to access the right information at the right time was vital and this could be achieved in part by having information pathways that respond to need (Robinson *et al.*, 2009). However the authors acknowledge that the research concentrates predominantly on information around diagnosis and how to access services in Tasmania, therefore whether these findings can be generalised to a wider population remains unresolved.

Therefore, the research by Robinson et al. (2009), points to the importance of timeliness in receiving information, additionally the CMIS also identifies that both the form and type of information is also important and individual in nature. It has been hypothesised that individuals may utilise different sources of information for different needs, for example health professionals may be accessed for cognitive advice and peer groups used for reassurance and affective information (Harland and Bath, 2008).



(Johnson and Meischke, 1993)

*Figure 14. Comprehensive Model of Information Seeking*

Previous research has studied the information needs of caregivers for PwD and identified that information which offers ways of coping with behavioural difficulties are felt to be the most needed (Nichols *et al.*, 2009; Koenig, Steiner and Pierce, 2011; Steiner, Pierce and Salvador, 2015). Studies also conclude that these information needs are individual in nature and should be able to adapt to the changing needs of carers and PwD (Washington *et al.*, 2011; Suhonen *et al.*, 2015). However research has stopped short of identifying how and where caregivers would like to receive this information for it best to meet their own needs. There also remains a lack of clarity as to where carers currently look for information. It was hypothesised by Harland & Bath (2008) that PwD may exhibit different preferences depending on their type of need, for example a need to increase understanding may be best met via written material, and conversely information needed to reassure may be best provided by a support group. However this theory was not empirically tested.

## 6.2 Problems with information provision

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Various studies have found that PwD and their carers feel that they do not have access to sufficient appropriate information about aspects relating to the condition. For example, a study by Edelman et al. (2006) found that family carers and the recipients of their care who had a diagnosis of dementia (n=100 dyads) had differing information needs both with regards to the types and sources of information. In ten percent of dyads, care recipients expressed interest in support groups where their family carer did not feel that this was important. Perhaps the most significant finding was that although participants were on average two years following diagnosis they still expressed a need for basic information and advice which led the researchers to hypothesise that this may be due to these needs not being met by health professionals following diagnosis. This study highlights the need for dementia sources and advice which is specifically aimed at different stakeholders and adaptable to their individual requirements.

The NICE Quality Standard addressing support in health and social care for PwD which was published in 2010 aims to address some of these issues. Within the standard it says that all those who are newly diagnosed with dementia and their carers receive both written and verbal information about the condition, local support services and treatment. The quality standard does not prescribe the scope or range of information that this advice should contain (National Institute for Health and Care Excellence, 2010). There are no defined quality standards which address the provision of information later in the disease process, for those who have received a diagnosis some time previously. Due to the progressive nature of dementia, it is likely that information needs change over time.

### 6.2.1 Passive and Active Information

If we examine evidence from information science, there are two different ways in which information can be found: Passive information is that which is received by an individual without being sought (Johnson and Case, 2012). This type of information is largely present in the broadcast and printed media but can also be received in patient

information leaflets and guides from health and social care services for example. Active information is that which is purposefully obtained through actively seeking it out. Today, perhaps the most common form of active information seeking is to perform an internet search but active information can be found from other sources such as health professionals or peers (Harland and Bath, 2008).

### **6.2.2 Tacit versus Explicit knowledge**

Two fundamental information types have been described. Tacit knowledge was first described by Polanyi (1983) and refers to knowledge gained through experience and is not easily described or written down. Tacit knowledge is most commonly stored within the individual. Tacit knowledge by definition is most likely to be gained through personal experience but can also be sought through contact with others who have been through similar experiences through support networks, friend and family. In a healthcare context, online forums have been shown to provide particular tacit knowledge regarding how individuals can navigate healthcare systems and bureaucracy by allowing the dissemination of personal experiences from a wide population (Foster, 2016). This in turn empowers patients and their carers to be consumers of healthcare and make informed decisions.

Explicit knowledge relates to procedures and fact which is more easily quantified and stored or written down. Within healthcare this can be provided as factual advice from health and social care professionals through both face to face and published materials.

### **6.2.3 Quality and Accessibility**

Information science has defined two key concepts in the selection of an information source by individuals: Accessibility relates to how easily an information source can be reached. Quality is a diverse characteristic related to the accuracy, usability and comprehensibility of the information provided by a source (Zimmer, Henry and Butler, 2007; Lu and Yuan, 2011)

It has been shown that accessibility is the most influential characteristic on an individual's choice of information source, meaning people will choose a lower quality



but easily accessible information source over a high quality but inaccessible one (Zimmer, Henry and Butler, 2007). Accessibility for people caring for a loved one with dementia is directly linked to how much time it takes to use a source of information. Looking after a PwD takes a great deal of time and energy, which directly impacts on the time available to look for information (Harland and Bath, 2008). Conversely Pettigrew (2000) found that nurses who showed understanding and gave emotional support were regarded as more helpful to their patients regardless of the quality of information they gave. This points to interpersonal elements having an important influence on healthcare information provision.

#### **6.2.4 Relational versus Non-relational sources**

Information sources are also able to be separated into two types: Relational sources are those which are accessed via interpersonal information directly from another person which is particularly good for tacit knowledge. Non-relational information sources do not require direct contact with an individual (Zimmer, Henry and Butler, 2007; Lu and Yuan, 2011).

The type of information source accessed has been shown to be linked to information need. Information need is described as the amount of further information that is required to be able to complete a task which entails receiving enough information to be able to make decisions and have no further need for information on a given topic.

Lu and Yuan (2011) found that when information need was high there was a greater degree of uncertainty in participants which lead them to seek out relational information sources as this provided timely feedback and developed interpersonal ties which then reduced ambiguity for the information seeker. This is somewhat supported by Pecchioni & Sparks (2007) who surveyed individuals with cancer and their family members (n=168) regarding their preferred information sources. They found that interpersonal (relational) sources were more frequently used than mediated (non-relational) sources. Their results also indicated that whilst doctors were deemed the most important information source, participants were not as satisfied with them as other sources (Pecchioni and Sparks, 2007).

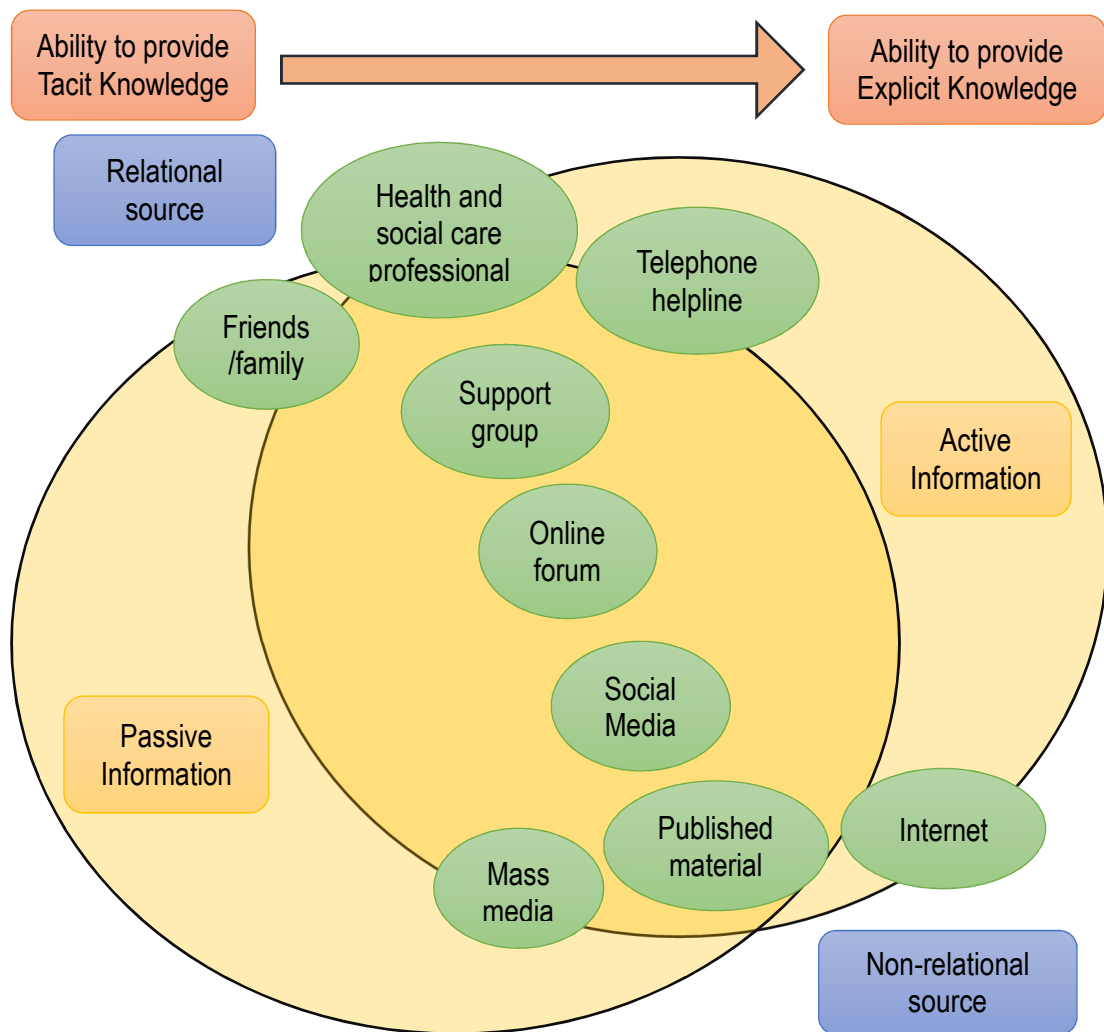
Low information need meant that participants were more easily able judge the information they receive from non-relational sources as they could use their own internal reservoir of knowledge (Lu and Yuan, 2011). However studies within healthcare have considered that information source selection may be contextual and also connected to affective and cognitive needs of the information seeker (Harland and Bath, 2008).

### **6.2.5 Relationship between factors**

To help to understand the relationships between aspects of information sources which have been discussed in the literature, I have shown them within a simple framework (Figure 15), which demonstrates the interplay of factors in relation to each other. There are few information sources that can be categorised distinctly and independently of others. Online forums for example can be regarded as a non-relational source if simply viewed, however these forums encourage active participation with other individuals which can be then categorised as a relational activity. In the same way forums can share experiences of others and therefore attempt to portray tacit knowledge of those providing input or purely explicit knowledge shared for all.

A review of a social media community for people with Young Onset Dementia found that users initiated private contacts outside of the social media environment which then lead to a sharing of individual perspectives to help address specific challenges (Craig and Strivens 2016). In this way the information moved from being non-relational, passive and more explicit in nature to become relational, active and able to address more tacit knowledge.

The patterns of moving between different sources of information for cancer patients was the focus of a study by Nagler et al. (2010). Their interviews (n=43) highlighted the role of proxies in signposting to other sources of information and therefore they have an essential role in filtering information in order to prevent information overload. They also found that new media (the internet) was predominantly used by this population for clarification of information provided by health practitioners.



*Figure 15. Interplay between Information source characteristics*

In media complementarity theory it is thought that individuals do not swop completely to new forms of media when they become available, but rather use them to complement each other (Dutta-Bergman, 2004). For example Tian and Robinson (2008) found that Americans who paid more attention to health information on the internet also paid more attention to other sources of information and also predicted the number of visits they made to health care practitioners. Further research is needed to discover what the relative interplay between these sources is, and how does information need reflect in the choice of information source.

A further study from Canada assigned volunteers with Multiple Sclerosis (MS) to either a focus group (n=7) or a telephone interview (n=14) with the aim of exploring how people with MS look for information regarding physical activity using the CMIS as a

framework. Contrary to the work by Bishop et al. (2009) they found that although healthcare professionals were a credible source of information, participants felt that doctors were often unhelpful as they lacked specificity and were the least accessible source (Sweet *et al.*, 2013). The internet was described as the most accessible place to find information but also less credible, therefore highlighting the compromise in information seeking between accessibility and quality as described by Lu & Yuan (2011). A possible compromise for this is suggested in that participants trusted some MS specific websites such as the MS society of Canada but this does not then address issues relating to the appropriate timeliness of the information, nor does it introduce individualised information also regarded as important by the people with MS interviewed here.

### 6.2.6 The Internet

Family carers of PwD frequently use the internet to research information about dementia and it is seen as an essential source of information for PwD and informal care givers. For the majority of people it is quickly accessible and offers a very broad range of advice (Kort S.M. and van Hoof, 2014). Kort S.M. & van Hoof, (2014) used a participatory design process to create a website resource regarding home modification in the Netherlands. The process included using focus groups made up of from dyads of a PwD and their carer. In the twelve months following the launch of the website it was viewed more than 13,000 times but 37% of these did not explore beyond the first page and less than 20% visited the site a second time. Therefore it was concluded that the end usability of the site for this population needed further investigation (Kort S.M. & van Hoof 2014). However the participant numbers were small, being only three couples involved and the information provided was specific to the Dutch Social Support Act, therefore may not be generalizable to other populations.

There is also a wide discrepancy in the amount and quality of the advice offered regarding dementia. Websites which appear at the top of the most common searches are not those who give the most evidence based or broadest information (Anderson et al. 2009). The ability to evaluate the quality of online resources has been tested

through research, the Dementia Caregiving Evaluation Tool (DCET) was proposed by Bath and Bouchier (2003), as a way of carers evaluating the sources of information they use. The resulting tool includes 47 questions and tick box answers regarding the information offered. The DCET does not allow for specialist dementia websites which may concentrate on specific areas such as environmental design and instead deals with generic care information. The length of the tool and its emphasis on the breadth rather than quality of information mean that its practical application remains limited (Anderson, Nikzad-Terhune and Gaugler, 2009).

Searching for information from online sources is a complex task which requires good levels of cognition especially for older people who lack long term experience in using the internet (Sharit *et al.*, 2008). Specifically memory and recall were found to be critical skills in the planning of an internet search strategy among older people.

#### **6.2.6.1 The influence of age on internet use**

Only 59% of households in the UK which contain at least one adult over 65 have access to the internet (Office for National Statistics, 2015). However use of the internet amongst people over 65 is growing. The same statistics also show that 71% of adults over 65 had used the internet in the preceding three months. In 2014, Fischer *et al.* discussed the differences in Health Information Technology use between younger seniors (60-80 years) and older seniors (over 80 years). They found that significant differences were present between these two age categories in relation to their feelings about accessing the internet. They hypothesised that this occurs because younger seniors have retired from work more recently and therefore were more likely to have experience of the internet within their working life (Fischer *et al.*, 2014). Searching for information from online sources is a complex task which requires good levels of cognition.

Whilst there is a lack of studies examining the information delivery preferences for people with dementia, there is a body of research evidence exploring where people with MS, find information. MS like dementia, is a long term progressive condition. Bishop *et al.* (2009) questioned people on the National Multiple Sclerosis Society

mailing list in the United States (n=409). Participants selected one place that they most often seek information from a list of five options. Doctor or neurologist was the most preferred source (31.69%) followed by the internet (27.94%). They found that use of the internet was inversely proportional to age. In fact, age was a consistently significant factor in predicting information source use. They also found that there were significant correlations between personal profile and use of different information sources. For example they found that people more likely to use the internet were those who were married, younger, female and employed full-time but this research does not offer any indication of what the causal relationship might be. The research was further limited (as acknowledged by the authors) by only allowing one choice of information source, which is unlikely to give an accurate picture of the actual situation.

### 6.3 Information source preference and dementia

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Recent research by Killen et al. (2016) investigated the information source preferences of people following a diagnosis of dementia with Lewy bodies. They conducted an online survey from a Lewy body charity website. The research found that the preferred method of receiving information was at a support group specifically designed for PwD involving Lewy bodies. However respondents were limited in their choice of answer to small groups with patients separate, joint small groups or individually (Killen *et al.*, 2016). Therefore media, internet and published information sources were excluded. Additionally conducting the survey exclusively online is likely to have biased the results.

A study by Suhonen et al. (2015) surveyed significant others (n=264) of people with memory disorders (including dementia) who were living in formal homecare or newly admitted to residential care in Finland. They found that participants lacked knowledge about care and services specific to their significant other. They concluded that there was an inability of health professionals to tailor the information to the individual which then impacted on both how useful and how understandable it was. They concluded that information could be improved by collaborative working between professionals

and health sectors. They also indicated a need to explore the preferred methods of receiving information by PwD and their significant others.

### 6.3.1 Topics of information

The information needs of PwD and their carers has also been a topic of a limited number studies. Overall these show that carers are predominantly concerned with receiving information regarding how to manage behavioural symptoms linked to dementia (Nichols *et al.*, 2009; Koenig, Steiner and Pierce, 2011; Steiner, Pierce and Salvador, 2015; Killen *et al.*, 2016). However there are methodological limitations that may have affected results. The studies by Killen *et al.* (2016), Koenig *et al.* (2011) and Steiner *et al.* (2015) offered a limited choice of topics from an investigator compiled list for participants to pick from which may have introduced bias.

Research by Nichols *et al.*, (2009) used a secondary analysis of data obtained during a feasibility study of a new care program in Memphis, Tennessee. They found that the most common topics that carers (n=165) requested to talk about during primary care visits were communication (26.1%), combativeness (conflict) (28.5%) and confusion (26.1%). Additionally activities were requested 34.6% of the time, however this was also the default topic chosen by the researchers if participants did not indicate any specific needs, therefore it is unclear whether this represents an area of concern or the level of carers with no specific concerns.

Furthermore this study found that there were notable differences between the information requested by those with mild versus severe dementia and between those who care for a spouse as opposed to non-spouses. For example spouses requested more information relating to grief and dealing with their feelings (Nichols *et al.* 2009).

## 6.4 Concluding thoughts on sources of dementia information

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The literature shows us that there are many factors which influence the use of different sources by those who have an information need. Internal factors such as

past experiences, perceived quality and credibility have been shown to affect information source selection and use. What is less well understood is how these factors influence the choice of people who are looking for dementia specific information. This is important because people with dementia and their loved ones have been shown to feel that they are not gaining the information they need to live with the condition effectively.

Therefore, to investigate how these aspects affect PwD and their close family and friends in searching for information, a study was designed to discover where this group find information about dementia, why these sources are used and how they feel about the sources of dementia information which are available to them.



7 Information source preferences and use among family and friends of those with dementia.

## 7.1 Introduction

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The previous Home Adaptation study (Chapter 5) suggests that PwD and their carers feel that they do not receive enough information to meet their needs and therefore they feel uninformed and lack vital information. This is despite a wide range of information sources being available. Therefore, it remains unclear where PwD and their carers currently obtain information from and what their preferences of information delivery are. Additionally it is unclear whether the use of information sources is affected by perceived credibility and usability as discussed in Chapter 6.

Understanding the relationship between the information sources used by an individual, their perceived quality and knowledge outcomes are important to fully understand why home adaptation recommendations are not being used by PwD living at home. Therefore, a study was designed to discover where PwD and those close to them look for information and what perceptions exist of the information found via different sources, in order to identify how information can be better targeted to individuals within this population.

### 7.1.1.1 Research Questions

- Where do PwD and their carers currently access information regarding dementia?
- How accessible, trustworthy, credible and comprehensible do PwD and their carers consider the available sources of information?
- How would PwD and their carers like to receive information?

In order to answer the research questions a nationwide mixed methods survey was carried out in the UK using online and hard copy responses. Participants who have a close friend or relative with dementia were invited to participate as they were most apt to search for information about dementia.

## 7.2 Methods

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### 7.2.1 Recruitment

The 'Join dementia research' (JDR) database was used as a recruitment tool as described in Chapters 5 and 6. Alongside JDR, secondary recruitment was via posts on social media (Twitter and Facebook), a post on the Talking Point online dementia discussion forum and posters displayed at a variety of settings including libraries and public notice boards including those in shopping centres and supermarkets. Prospective participants were directed to either the URL for the questionnaire or to contact the chief investigator for a printed participant pack as per their preference.

The JDR register records were searched using the inclusion criteria against the information provided by volunteers. All matched participants were screened by the chief investigator those who continued to meet the inclusion criteria were then contacted and invited to participate. They were sent an invitation to participate and a Participant Information Leaflet (PIL) via email or post along with a copy of the questionnaire (The PIL, Consent form and questionnaire can be found in Appendix F).

#### 7.2.1.1 Inclusion Criteria

- Has a close family member or friend with dementia who lives at home. This study is part of a wider research project looking at how PwD live their lives at home.
- Over 18 years of age. Therefore able to give consent autonomously and to have the ability to make decisions regarding the home environment.
- English speaker. All survey literature was written in English and due to budget and time restraints translation and interpreters were not able to be used.

#### 7.2.1.2 Exclusion Criteria

- Has a family member or friend with dementia who lives in residential care. Residing in residential care potentially changes information need and adds extra elements to information searching such as nursing home staff.

- Does not have a close family member or friend with dementia. This study focusses on individuals with a high level of information need, those without close relatives or friends with dementia are less likely to have specifically sought dementia information and advice.
- PwD wishing to complete the questionnaire alone. As the questionnaire was completed remotely we were not able to assess the capacity and ability of an individual with dementia to complete the questionnaire accurately, therefore participants with dementia were only used if they completed the questionnaire with a family member or friend.

Individuals with dementia who wished to make their thoughts about information sources known, were permitted to complete the questionnaire with the aid of a family member or carer as a dyad. Screening questions at the beginning of the questionnaire identified this group, allowing a comparison of the two participant groups (carer / family member alone and carer / PwD) to be made.

### 7.2.2 Study Type

A study specific questionnaire was developed. The questionnaire included a combination of closed and open questions as shown in Appendix E. The questionnaire underwent a process of design including the formation of questions stemming from data collected from the Home Adaptation study (Chapter 5) and previous literature. Questions regarding computer, internet and passive information use were adapted from the U.S. Health Information National Trends Survey (HINTS) (National Institutes of Health and Services, 2014).

The questionnaire began with obtaining informed consent and a screening question relating to participants being related to or friends of a PwD. The second section collected demographic information.

The third section related to passive information followed by active information seeking, support groups and the internet. The questionnaire also asked respondents to rate the trustworthiness, comprehension and accessibility of a variety of dementia

information sources and where they would seek information on a variety of topics. The final section asked about overall feelings about the provision of dementia information and which aspects were considered most and least important for a source of information.

Both online, postal and telephone versions of the questionnaire were provided. These options were offered in order to reach a wide cross section of the population, especially given that there was an increased chance that older participants would not have online access (Office for National Statistics, 2015). A copy of the postal questionnaire can be found in Appendix G.

The online questionnaire was built and distributed via Bristol Online Surveys which is an online survey platform accessible and licensed to the University of Warwick and enables a survey specific URL to be created. Bristol Online Surveys then allows data to be uploaded directly into NVivo and SPSS software for analysis.

### **7.2.3 Piloting**

The questionnaire was reviewed for clarity by an Occupational Therapist with significant experience working in the community with PwD and their carers, it was then piloted with two carers of PwD known to the researcher in order to assess the content and clarity of both the online and postal versions. Following the questionnaire pilot minor changes were made to the wording and grammar of some questions.

### **7.2.4 Data Analysis**

To test the first aim, descriptive statistics from questions relating to active and passive information source use were used. Spearman's Rho Correlations were calculated between demographic characteristics such as age and level of education and use of different information sources and then between which information sources were used against how participants feel about their search for information and their level of knowledge.

Frequencies were also calculated for information source preference for a range of different topics in order to try to identify if information source use depends on the topic of information required.

To test the second aim, positive, neutral and negative descriptive statistics were calculated. Spearman's Rho correlations between the information sources used and overall feelings towards those sources were calculated. Personal Likert responses for effort, frustration, quality and comprehension were combined to create a Likert scale for each respondent's information seeking (Bradburn, Sudman and Wansink, 2004).

The third aim was tested via open responses which were then analysed using thematic analysis. Codes relating to topics and frequencies were used to define participant preferences for information delivery. Finally this was cross referenced to findings from the first two aims to generate a discussion.

Open questions providing qualitative data were entered into Nvivo10 software and thematically coded in a process of interpretive analysis (Smith & Osborn 2007). This analysis involved initially reading the responses to gain an overview of the comments, then rereading to draw key points and statements from the answers to produce overarching themes. These themes were then used to enrich the results from the quantitative data.

## **7.2.5 Ethical Consideration**

JDR which was used for recruitment for the study is funded by Department of Health and is Health Research Authority (HRA) endorsed. The online service and all associated documentation; methods of contacting volunteers and handling of data, were reviewed by a specially convened HRA committee which included experts in research ethics, data protection and information governance. Formal endorsement was issued by the HRA in a letter dated 20 May 2014 (National Institute for Health Research, 2014).

The study was given ethical approval by the University of Warwick Biomedical and Scientific Research Ethics Committee. Study number REGO-2016-1826. 20<sup>th</sup> May 2016.

## 7.3 Results

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A total of 214 completed questionnaire responses were received via online (n=197) and by post (n=15) between 26<sup>th</sup> August and 30<sup>th</sup> December 2016. No participants requested a telephone questionnaire. Only two respondents indicated that there were completing the questionnaire alongside a participant with dementia. All other respondents were carers who completed the questionnaire independently. Two postal replies were not included for analysis as participants indicated that their relative was now living in a residential care setting. The results and analysis are therefore based upon 212 responses.

### 7.3.1 Characteristics of the sample

The mean age for respondents was 57 years (SD +/- 10.6) and the mean age of those they care for was 79 years (SD +/- 12.6). Replies were received from all four countries of the United Kingdom as shown in Table 6.

	England	Scotland	Wales	Northern Ireland
Number of respondents	140	43	25	2
Percentage of total	67	20	12	1

Table 10. Where do you reside?

The results here do not exactly represent the population ratios seen in the United Kingdom population as a whole, with slightly fewer English and Irish and more Welsh and Scottish than would be representative. Figures from the Office for National Statistics report 84% of the population reside in England, 8% in Scotland, 5% in Wales and 3% in Northern Ireland (Office for National Statistics, 2016).

Gender of participants was skewed towards a female bias with 80% of respondents being female. National statistics show that in the UK between 60-70% of informal carers for PWD are women, which means the sample has more female participants

than would be expected. 57% of the family member or friend with dementia were female this is slightly fewer than the national average which shows 61% of PwD in the UK are female (Alzheimer's Research UK, 2015).

Gender	Respondents	Friend or family member with dementia
Male	40	89
Female	171	121

*Table 11. What is your gender?*

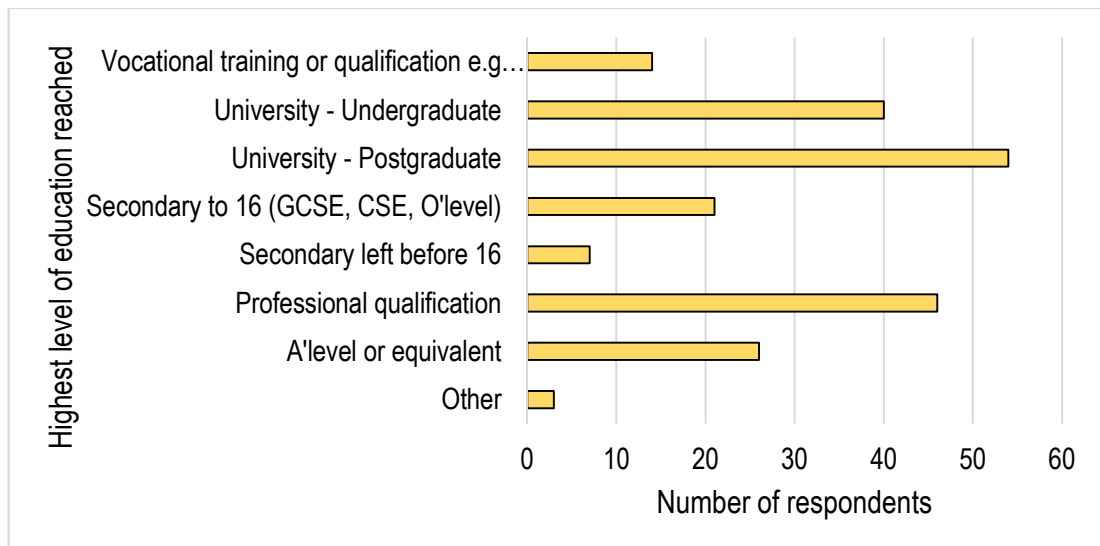
The sample was predominantly composed of those from a white/white Irish/white other ethnic group.

Ethnicity	Respondent		Friend or family member with dementia		UK percentage (Office for National Statistics, 2012a)
White/White Irish/White other	208	98%	206	97%	86%
Asian / British Asian	2	0.9%	2	0.9%	7.5%
Black/African/Caribbean/Black British	1	0.5%	1	0.5%	3.3%
Missing	1	0.5%	3	1.4%	N/A

*Table 12. How would you describe your ethnicity?*

The majority of respondents have been educated beyond age 16 (n=134). The largest group were educated to postgraduate level (n= 54) and n=46 held a professional qualification.





*Figure 16. Highest level of education achieved by respondents*

The large majority of respondents had a parent with dementia (n= 177) with a comparatively low number who were caring for a spouse (n=24) or friend (n=2)

Relationship to PwD	Number of responses	%
Son / Daughter	177	83
Spouse / Partner	24	11
Grandson / Granddaughter	2	1
Friend	2	1
Brother	2	1
Missing / not answered	5	2

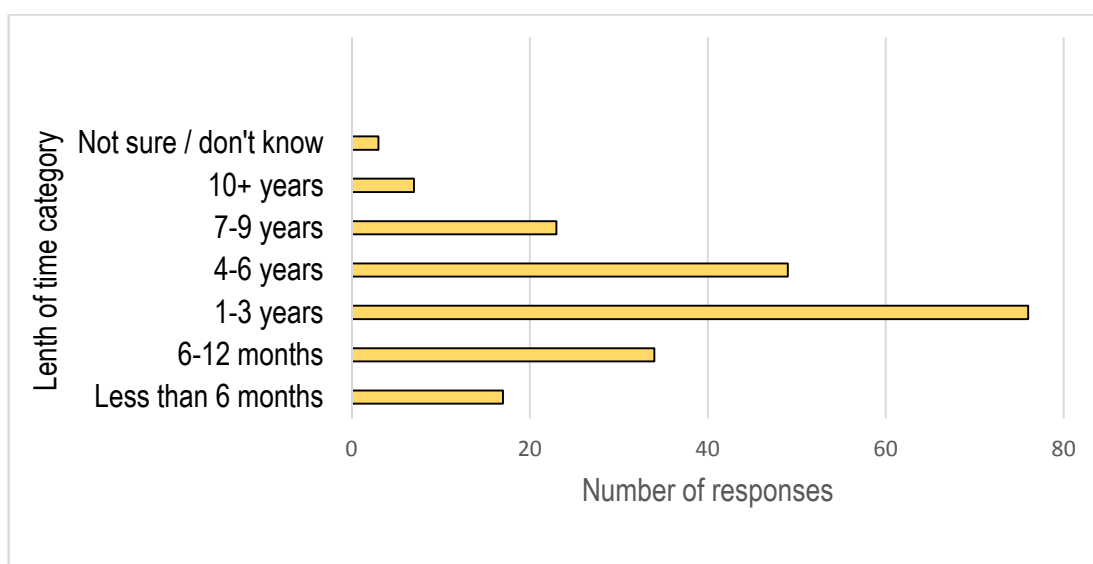
*Table 13. Relationship of respondent to PwD*

The distribution of different types of dementia diagnosis amongst the friends and family of respondents were comparable to the recognised distribution of the condition, with Alzheimer's disease the most common (n=99) followed by Vascular Dementia (n=53), Frontotemporal Dementia (n=11) and Dementia with Lewy Bodies (n=11).

Dementia type	Number of responses	%
Alzheimer's Disease	99	47
Vascular Dementia	53	25
Frontotemporal Dementia	11	5
Dementia with Lewy Bodies	11	5
Mixed Alzheimer's Disease and Vascular Dementia	9	4
Other	7	3
Dementia following stroke	6	3
Posterior cortical atrophy	2	1
Mixed Frontotemporal and Vascular Dementia	2	1
Not sure / don't know	10	5

*Table 14. Type of dementia diagnosed*

The majority (n=127) had been living with a diagnosis of dementia for less than 4 years, with the peak number of respondents having had a diagnosis one to three years ago (n=76). This is due in part to the degenerative nature of the condition and the inclusion criteria of being a relative or friend of someone with dementia who is living at home and may indicate that those who have had the condition for longer are more likely to live in residential care.



*Figure 17. Length of time since dementia diagnosis*

### **7.3.2 Where do PwD and their family and friends currently access information regarding dementia?**

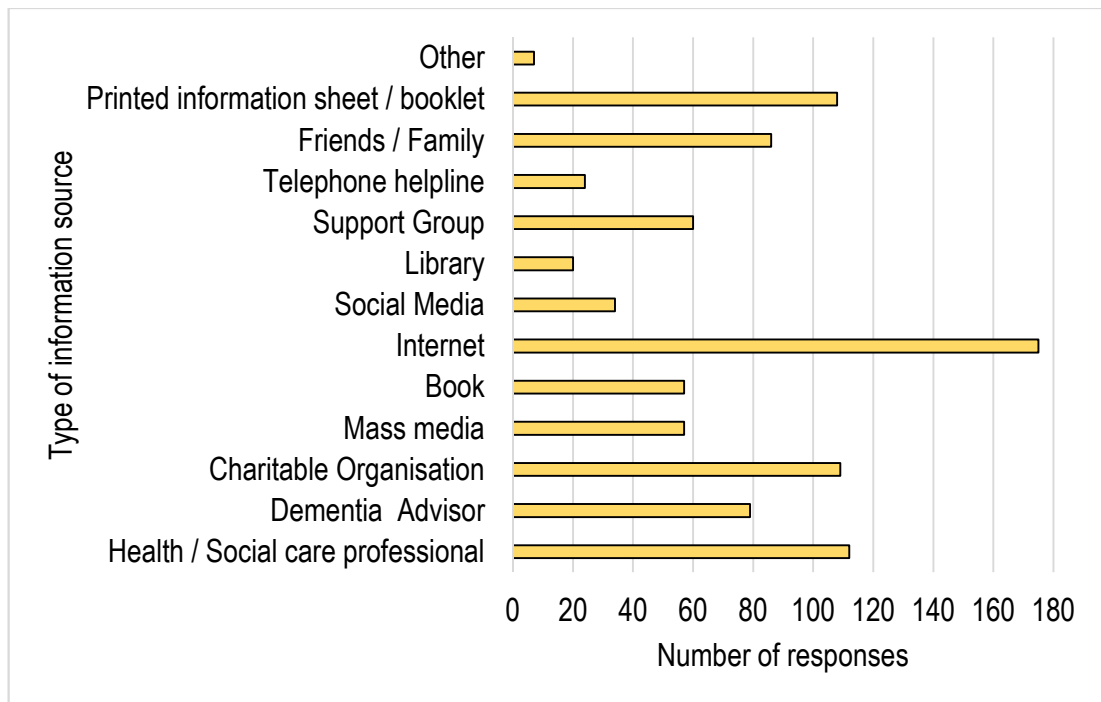
Overall respondents indicated that they accessed a wide range of information sources to find information about dementia.

#### **7.3.2.1 The internet**

Only two respondents stated that they do not go online to either access the World Wide Web or use e-mail. The remaining participants stated that they use the internet to access both the World Wide Web and to use e-mail. The internet was the source most commonly used by participants to actively search for information about dementia (n=175) which equates to 82% of respondents, followed by health and social care professionals (n=112). It is interesting to note is that 99% (n=210) of participants state that they went online to access the World Wide Web. Therefore there are 17% (n=35) of respondents who indicate that they are able access and use the internet but do not then use it to search for information regarding dementia.

#### **7.3.2.2 The effects of age**

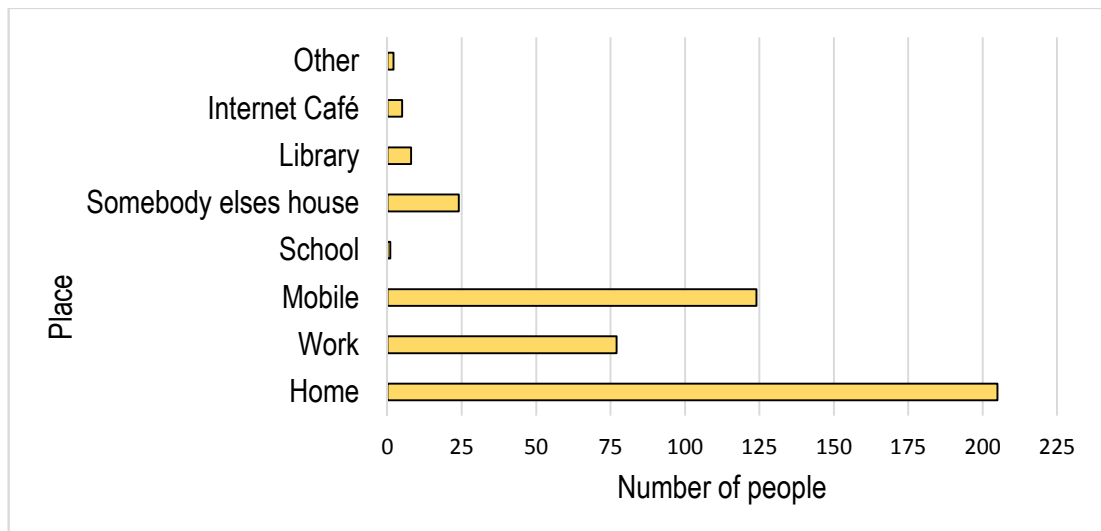
Age correlated with the number of times a week the internet was used (Spearman's rho, 2 tailed test  $r=-0.182$   $p=>0.01$ ) and also to the likelihood of using the internet as an information source (Spearman's rho, 2 tailed test  $r=-0.145$   $p=>0.01$ ) meaning younger people were more likely to utilise the internet for finding information.



*Figure 18. Sources actively searched for information*

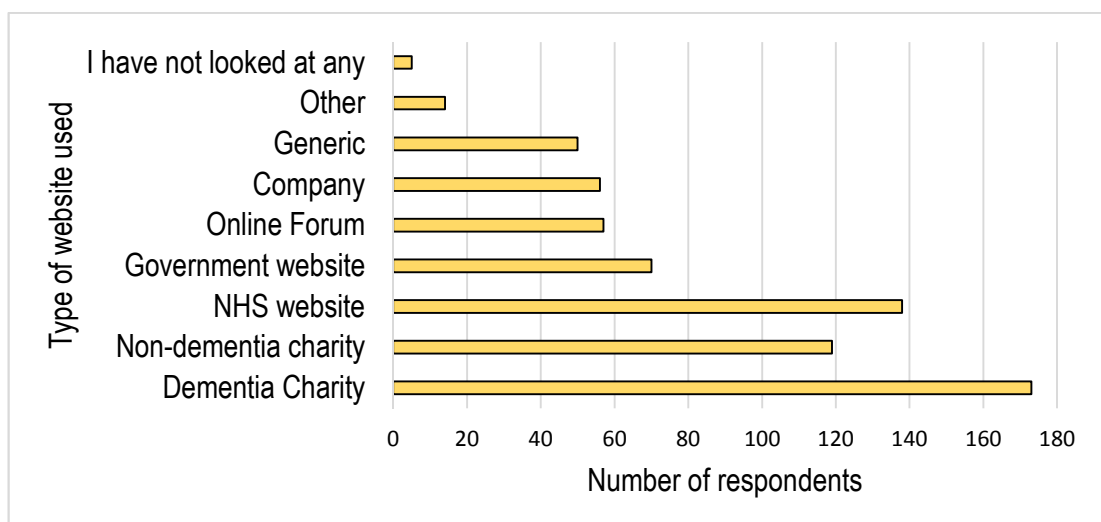
The mean number of information sources searched actively by participants was 4.4 (SD +/- 2.3) with a median of 4. This means a significant percentage of people reported using multiple sources to answer their queries. Perhaps not surprisingly there is a positive correlation between the number of websites used and both the number of times a week a participant accesses the internet (Spearman's rho, 2 tailed test  $r=0.233$ ,  $p=>0.01$ ) and the likelihood of using the internet for information searching (Spearman's rho, two tailed test  $r=0.314$   $p=>0.01$ ).

97% of respondents who use the World Wide Web do so at home, followed by 57% who access via a mobile device as shown in Figure 19.



*Figure 19. Where respondents use the internet*

The most common type of website used by people looking for dementia information were those produced by dementia charities (n=173 responses). On average respondents looking for information on the internet used 3.32 different types of website. There was a significant positive correlation between the number of different types of website used and the Likert scores for effort in finding information (Spearman's Rho, two tailed test  $r=0.142$ ,  $p>0.05$ ). Interestingly this means that the more websites used, the less effort participants found the search for information.



*Figure 20. Types of website used for dementia information*

When people were asked why they used the internet two themes emerged: habit and accessibility (See Figure 22).

For some, searching for information on the internet was an automatic response to a need for information. For others the internet represents the most accessible form of information seeking, it is open 24 hours a day and for some the only place they feel they can look and they are guaranteed to find information (even if it is not the information they require). Interestingly trustworthiness scored higher than accessibility as a preferred attribute to an information source, however participants would use a less trusted but more accessible source when the preferred source was not available.

Those who use the internet less often were more likely to feel able to manage all the information that they were offered, compared to those who accessed the internet more often (Spearman's rho, 2 tailed test.  $r=-0.220$   $p>0.01$ ).

### **7.3.2.3 Relational Information Sources**

The most used relational information source was a GP, with 187 responses, followed by friends and family with 145. Overall there were mixed views regarding healthcare practitioners as a source of information and advice. The majority of respondents ( $n=152$ ; 72%) had received passive information from GPs, of these 38% rated the information as poor or very poor (as shown in Table 15). This was further highlighted in the open responses where participants voiced negative feelings towards GPs as a source of information due to a lack of specific dementia knowledge or poor accessibility.

Relational Source	Total responses
GP	187
Friends and family	145
Dementia consultant	135
Other carers / PwD	127
Dementia nurse	93
<i>Social worker</i>	88
<i>Dementia advisor</i>	82
Occupational therapist	72

*Table 15. Number of respondents using relational sources*

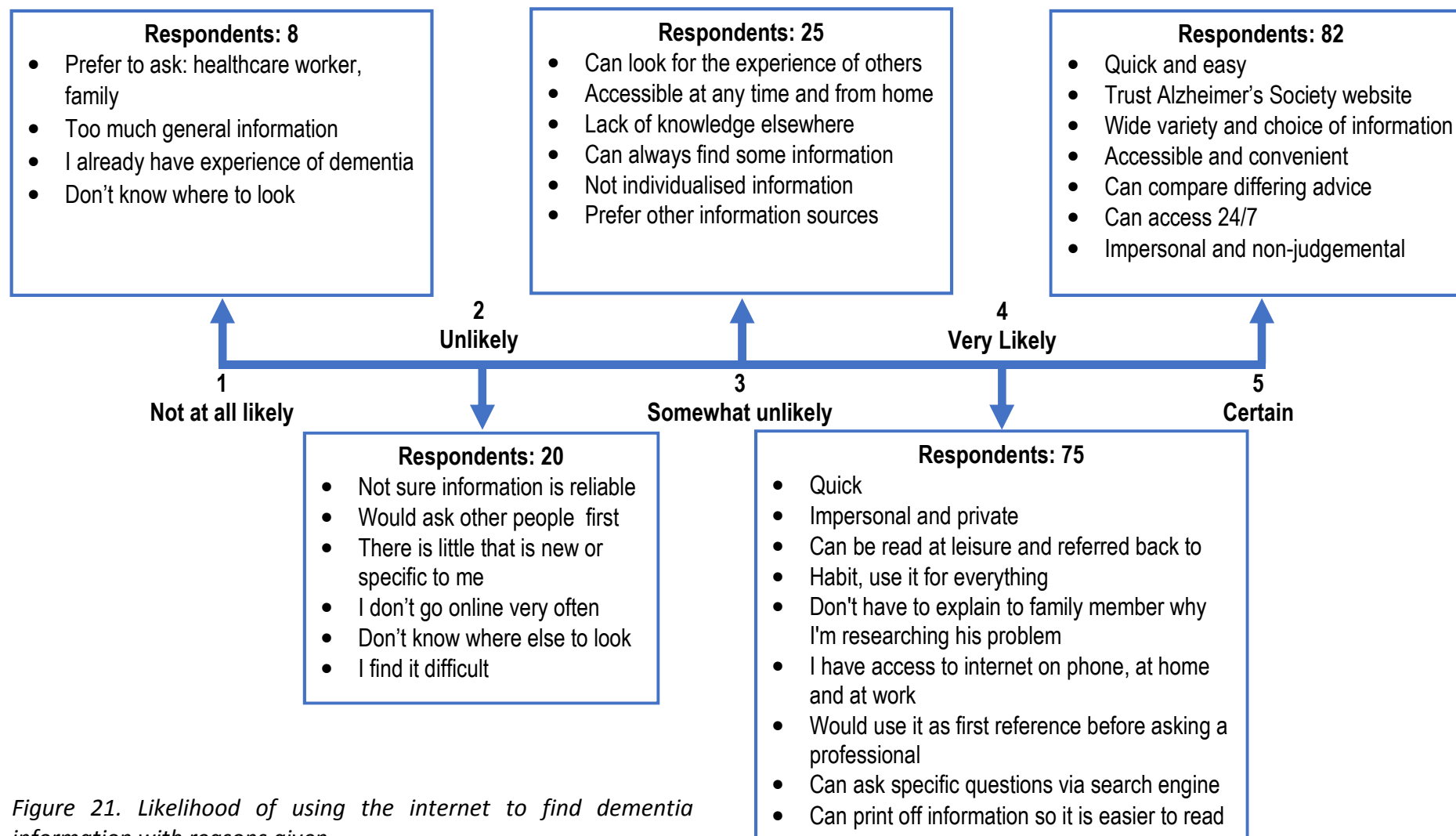


Figure 21. Likelihood of using the internet to find dementia information with reasons given



#### *7.3.2.3.1 Friends and Family*

Perhaps understandably friends and family were ranked as the most popular information source for emotional support with 66.5% of respondents indicating that they would go to friends and family first. However they rank lower than health care professionals and dementia advisors for practical advice, medication advice, and advice about how to manage memory loss and other symptoms as shown in Table 16.

Rank	Medications	Memory	Other symptoms	Equipment/ Living aids	Emotional support	Practical Advice
1	Health & Social care professional	Health & Social care professional	Health & Social care professional	Health & Social care professional	Friends & Family	Dementia advisor
2	Internet	Dementia advisor	Dementia advisor	Internet	Dementia advisor	Health & Social care professional
3	Dementia advisor	Internet	Internet	Dementia advisor	Health & Social care professional	Friends & Family
4	Friends & Family	Friends & Family	Friends & Family	Friends & Family	Support group	Internet
5	Published Material	Support group	Support group	Support group	Internet	Support group
6	Support group	Published Material	Published Material	Published Material	Telephone helpline = Other	Telephone helpline
7	Social media = Telephone helpline	Mass Media	Mass Media	Mass Media = Telephone helpline		Social Media = Mass Media
8		Telephone helpline	Social media = Other	Telephone helpline		
9	Mass Media	Social media		Social media		Published Material = Other
10	Other	Other	Telephone helpline	Other	Mass Media	

*Table 16. Ranked placings for where respondents would look first for information about a range of topics*

#### 7.3.2.3.2 Support groups

31% of respondents have attended a support group for carers. Of those that had not yet attended a support group 41% stated that they would consider attending one in

the future. Reasons for not considering attending a support group are summarised in Table 16.

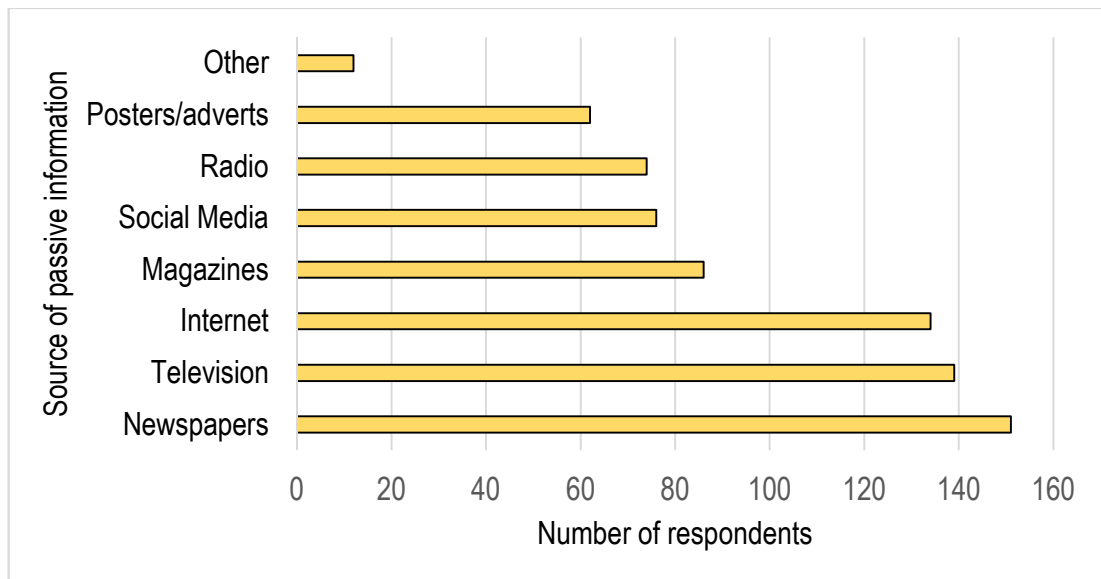
#### 7.3.2.3.3 *Passive Information Sources*

Passive information which was not specifically searched for was received from a number of sources. The mean number of different passive information sources which provided respondents with information was 3.5 (SD = +/- 1.7) with a median of 3 (Of these passive sources newspapers (n=151), internet (n=134) and television (n=139) were the most common ways to receive passive information).

<b>Reasons for not considering a support group</b>	<b>Frequency</b>
Prefer other information sources	4
It wouldn't help	3
I am not the main carer so not relevant to me	4
Would rather talk about other things	3
Lack of time	3
I don't like talking to strangers	2
It would be depressing	1

*Table 17. Reasons given for not considering a support group*

Passive information lead to further action by the majority of respondents (n=156). 73% of respondents has used information they had received passively to go on to make changes (12%) or seek further information (61%). Participants were openly asked to indicate how they had either sought further information or made changes following seeing or receiving passive information:



*Figure 22. From which sources have respondents received passive information about dementia*

Some responses here are not clearly defined. 21 responses indicated that the individual had looked for further information but not indicated from where. It is also unclear where the overlaps of sources lie, for example it is likely that some respondents contacted charities via online methods and some dementia training courses are provided online but the type of training course was not specified. Therefore, it is likely that 'Used internet' scores are under reported.

Response	Number of responses	How passive information was used	Frequency
Yes: By seeking further information	130	• Contacted charities	24
		• Used internet	37
		• Asked health care professionals for information regarding: <ul style="list-style-type: none"> <li>○ Medication</li> <li>○ Care services</li> <li>○ Financial assistance</li> <li>○ Equipment</li> </ul>	18
		• Enquired about research participation	16
		• Attended dementia training course	10
		• Bought book	3
		• Asked about Power of Attorney	3
Yes: By changing something	26	• Began attending carer or support group	12
		• Changed diet	6
		• Changed behaviour towards loved one	8
		• Actively sought out a diagnosis from doctors	3
No	55		

Table 18. Have you ever acted upon passive information?

### 7.3.3 How accessible, trustworthy, credible and comprehensible do PwD and their carers consider the available sources of information?

#### 7.3.3.1 Trustworthiness

On the whole trustworthiness scores showed a greater tendency towards a neutral response for each information source (mean 77.4 scoring neutral over all categories) than either understandable (mean 44.6 scoring neutral over all categories) or accessibility (mean 32.3 scoring neutral over all categories). A one way analysis of variance (ANOVA) showed this difference as significant ( $f=20.075$   $p=0.000$ ).

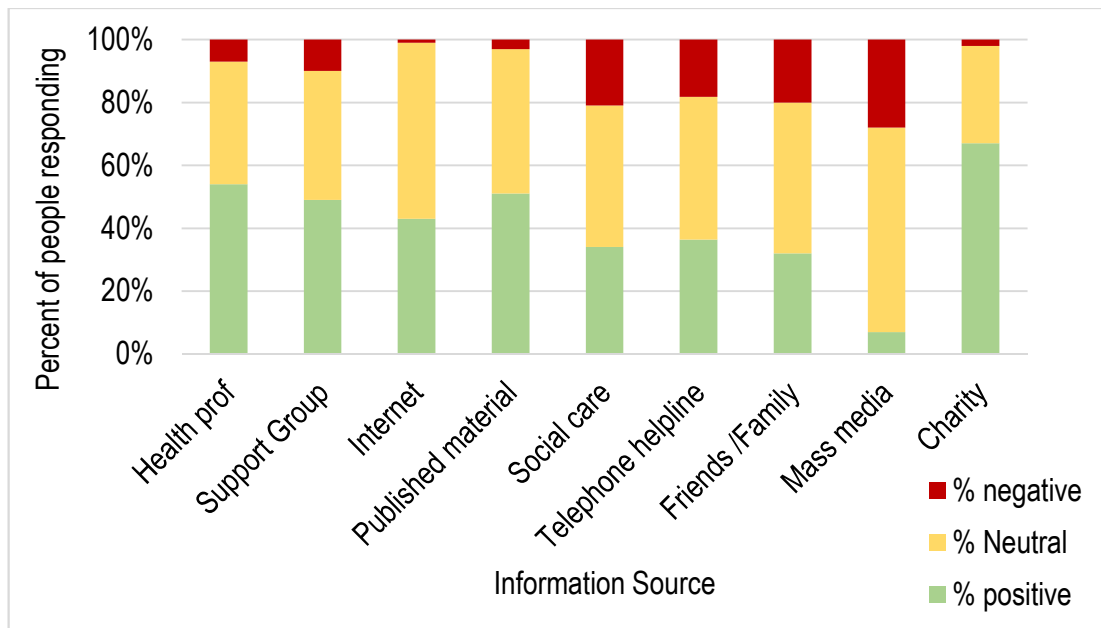


Figure 23. Perceived trustworthiness

Trust appears to have less influence over information seeking behaviour than other carrier factors. No significant correlation was found between scores for perceived trustworthiness of sources and their perceived quality or likelihood of use. For example participants who trusted internet sources more were not more likely to use it as an information source.

### 7.3.3.2 Accessibility

Health and social care professionals were viewed as the most inaccessible sources with 55% and 45% scoring their accessibility negatively respectively. The internet was regarded as the most accessible source of information (86% of respondents viewing internet accessibility positively), followed by published material (72%) and mass media (68%).

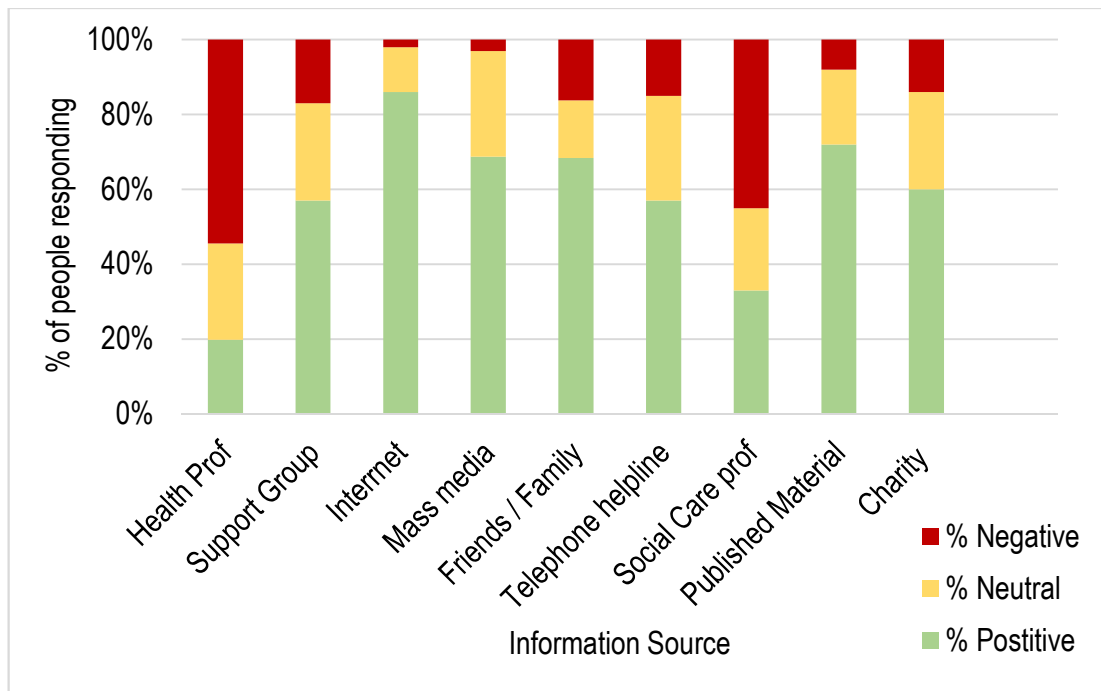


Figure 24. Perceived accessibility

A significant positive correlation was found between perceived accessibility of health professionals and the perceived quality of GP information Table 19. This indicates that for this population, the more accessible participants feel health professionals are, the higher they rate the quality of information they give. Interestingly this correlation was not seen between accessibility and other healthcare professionals (dementia specialist nurse, dementia consultant, other consultant, Occupational Therapist).

Correlation was also found between the perceived accessibility of the internet and the likelihood of internet use (Table 19).

	r	p
Quality of GP information	Health professionals 0.233	0.01
Likelihood of Internet use	Internet 0.229	0.01

Table 19. Spearman's Rho correlation co-efficient between accessibility and perception of information sources.

### 7.3.3.3 Comprehension

The sources of information offered were largely found to be understandable with the least understandable sources perceived to be telephone helplines (16% negative responses) and social care professionals (14% negative responses). The most comprehensible information was felt to be from charities with 81% people responding positively and support groups with 77% of people who had used them feeling the information they provide was understandable. This is perhaps not surprising as many dementia support groups are run by charities therefore it is reasonable that some of the information offered may overlap.

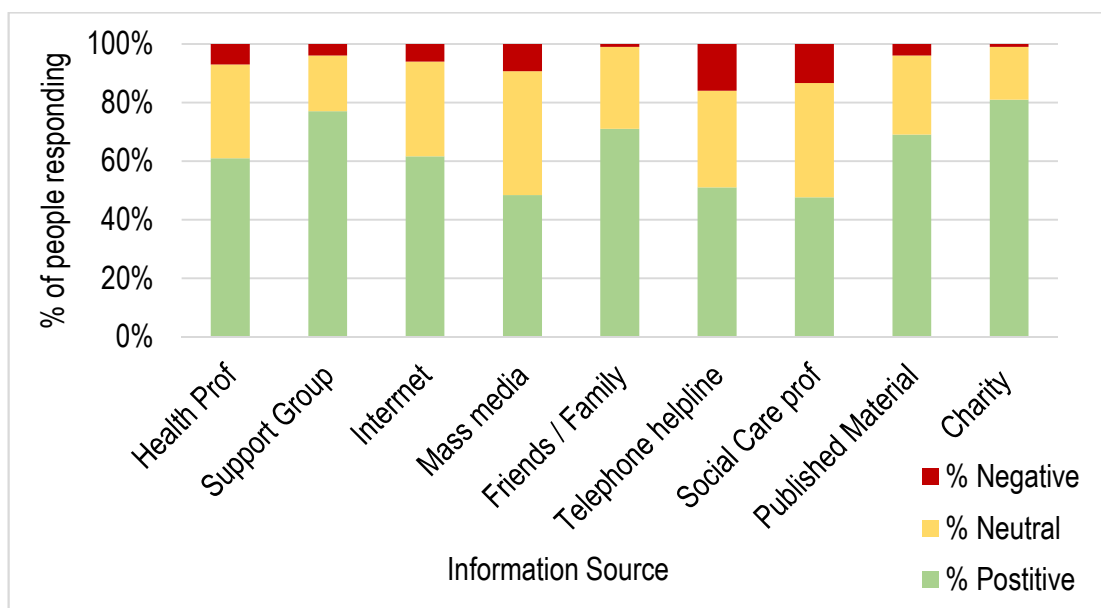


Figure 25. Perceived Comprehension

There was significant correlation between how understandable respondents found internet sources and the likelihood that they would use the internet to look for information about dementia (Spearman's rho, 2 tailed test  $r=0.180$   $p<0.01$ ).

### 7.3.3.4 Quality

When asked about their perceived quality of passive information received from several different relational sources there was less variation in perceived accessibility, trustworthiness and the ability to understand information for the internet than for other sources as shown in Figures 23-26.



51% of respondents felt that the information given by friends and family was of good quality compared to only 35% for GPs and 37% for dementia nurses. Friends and family also ranked highly for accessibility with 80% ranking it as easy or very easy to access, compared with 20% for health care professionals and 33% for social care professionals.

Other carers / PwD were regarded as a good quality source of information with 70% rating this information as good or very good. The poorest quality passive information was perceived as coming from GPs with 38% and Social Workers with 31% of respondents who had received information this way rating it poor or very poor.

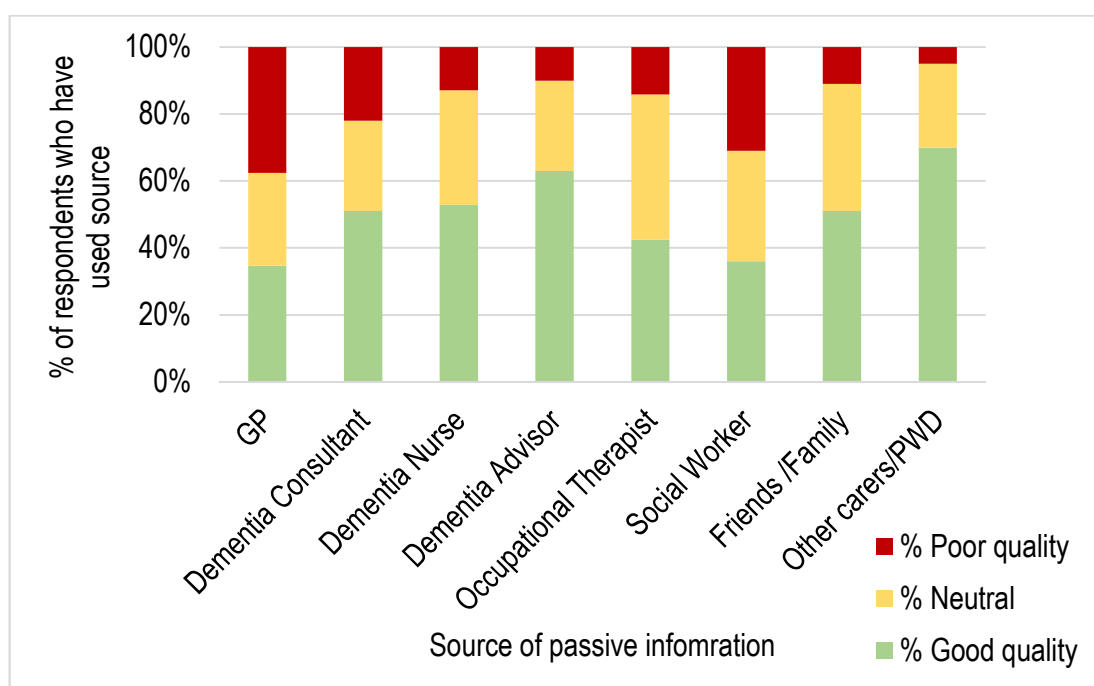


Figure 26. Perceived quality of passive information provided by relational sources

### 7.3.4 How would PwD and their family and friends like to receive information?

There was a link between how close to ideal participants felt that information sources are and characteristics linked to the gathering of the information.

	<b>Correlation with Closeness of current provision to ideal <i>r</i></b>	<b><i>p</i></b>
It took a lot of effort to get the information I needed	-0.394	0.01
I felt frustration during the search for information	-0.483	0.01
I was concerned about the quality of information	-0.294	0.01
The information was hard to understand	-0.286	0.01
I feel well informed about issues relating to dementia	-0.296	0.01
I have not received enough advice about dementia	-0.382	0.01

*Table 20. Correlations between Likert scores for how close to ideal is the current sources of information and experiences of information searching*

No link was found between these experiences of information searching and age. Participants who felt more confident in their ability to access information also felt that current information sources were closer to ideal than those who were less confident (Spearman's rho, 2 tailed test  $r=0.511$   $p>0.01$ ).

When respondents described how they would like to receive information many stated that they would like information to come from well informed GPs or health professionals (as described previously in Chapter 5).

Although 54% of respondents ( $n=115$ ) indicated that they agreed or strongly agreed that felt well informed about dementia, 41% ( $n=56$ ) indicated that they felt they had not received enough information about living with dementia. A small yet significant link was seen between the amount of time since diagnosis and how well informed participants felt (Spearman's rho, 2 tailed test  $r=0.164$   $p>0.05$ ).

Trustworthiness was the aspect of information most commonly described as the most important characteristic of an information source ( $n=128$ ) followed by easy to access ( $n=84$ ) and able to answer specific questions ( $n=86$ ). The least important aspect was offering a broad range of topic ( $n=77$ ) followed by that which includes the experiences of others ( $n=56$ ).

When asked in an open question how participants would ideally like to receive information about dementia the most common preference stated was from a well-

informed health professional (present in 57 replies) this could then be further broken down into dementia specialists (n=23) and more general health professional responses (n=34). The most common desire from participants was that health professionals should be better informed and specifically trained in dementia. 29 respondents listed the internet as a preferred method of receiving information with participants wanting a 24-hour accessible information option.

Interestingly, 24 respondents expressed wanting to be able to receive information via email. Reasons given for preferring email included being able to connect with knowledgeable professionals in a more accessible and private way Table 21.

Across both relational and non-relational sources there was a desire for individualised information from sources with a good depth of knowledge and provided at the most appropriate time as reflected by one participant: “Through a human who can consolidate best practice support for my local area, taking into account my mums situation and understanding how to help mum while she manages to stay in her own home” (Respondent 77).

Relational Information Sources as an Ideal Scenario		Non-Relational Information Sources as an Ideal Scenario	
Information Source	Frequency	Information Source	Frequency
Health Professional	34	Internet	29
Dementia Specialist	23	Email	24
Face to Face	21	Post	9
Support Group	7	Printed Information	9
Telephone support	4	Mass Media	2
Family/ Friends	2		

**Table 21. Relational and Non-relational sources identified as ideal by participants**

Accessibility and timeliness of support was also important to respondents. Eleven respondents described their ideal information source would be more accessible and thirteen felt that they would like information in a more timely way. Here there was a divided opinion as to the best way to received information following diagnosis, six participants felt that they would prefer more information at the point of diagnosis to

help guide them. However, four respondents felt that information would be better received via regular updates or printed information that can be used as a reference when they felt they needed it. This would prevent them from becoming overwhelmed.

#### **7.3.4.1 Education level**

The highest level of education participants received was linked to two aspects of information searching, being able to take in all of the information offered (Spearman's rho, 2 tailed test  $r=-0.189$   $p=>0.01$ ) and the number of websites used (Spearman's rho, 2 tailed test  $r=0.122$   $p=>0.05$ ).

## **7.4 Discussion**

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The purpose of this study was to investigate three issues; where PwD and their carers receive information and advice about living with the condition, how they feel about the available information sources and how they would like to receive information. More specifically the relative uses of both passive and active information along with relational and non-relational sources were explored. This culminated in identifying which sources of dementia information are characterised by key factors which have been shown to determine information sources selection, namely: accessibility, comprehensibility and trust. In support for previous research (Zimmer, Henry and Butler, 2007; Lu and Yuan, 2011), accessibility and quality were the predisposing factors relating to information source use.

Contrary to previous studies from employment and cancer information seeking (Pecchioni and Sparks, 2007; Lu and Yuan, 2011) family and friends of those with dementia appear to approach non-relational sources first as these are more easily accessible and able to give a broad range of answers. This is also apparent in the use of passive sources of information as a platform to then seek more information about specific topics. The cursory nature of information from mass media and TV serves as a brief introduction to which carers can assess the personal relevance and only seek information in more depth that is relevant to them.

Participants also express unhappiness with the lack of access to health professionals and also a perceived lack of knowledge of those professionals thus they lack both the quality and the accessibility needed by information seekers. This supports earlier research which found that accessibility is the most important factor over quality amongst company employees when choosing an information source (Zimmer, Henry and Butler, 2007).

Medical professionals, specifically GPs were mentioned more and offered greater influence over information seeking behaviour than any other relational information source. GPs are often the first contact a person makes prior to diagnosis and they will frequently be seen soon after a diagnosis which is the time when the information need is greatest. Therefore GPs represent a relational information source which is needed by individuals in order to then progress to using non-relational sources (Lu and Yuan, 2011). However the results here show that, at this point, participants found that the knowledge of health professionals did not meet their expectations and therefore their information need was not adequately addressed.

Johnson and Case (2012) describe the concept of 'information field' describing the types of information that an individual is exposed to on a daily basis. This is specific to the individual and is influenced by an individual's interest for health information and this in turn influences active information seeking. Information field changes when health interests change such as following a diagnosis of a lifelong condition (Johnson & Case 2012). This may explain why at the point of diagnosis, PwD and their loved ones frequently feel lost and need guidance (Chapter 5). It is possible that a diagnosis of dementia leads to a period of transition for an individual's information field, some will begin to notice dementia information from multiple sources and become overwhelmed and others will find their current information field does not provide the information they require.

Individuals would like GPs to be more accessible, however GPs already represent one of the more easily accessible health professionals as they are a frontline primary care contact which can then refer to other health services and practitioners (Department

of Health 2013). However, participants also felt that the current level of information provision by GPs lacks specificity and dementia specialism. This leads to frustration and a perceived inability to effectively seek information from non-relational sources as proposed by Lu and Yuan, (2011).

Participants who felt health professionals were more accessible also felt that GPs offered better quality information but it is unclear where the causal relationship lies. Whether being able to speak to healthcare professionals (of which a GP is one) makes individuals feel generally more positive about the quality of the information they are given or does receiving good quality information then mitigate perceived issues relating to accessibility?

The idea of having one-to-one discussions with knowledgeable people was a consistent theme amongst the open question responses regarding the ideal ways of receiving information. This was felt to provide all of the most preferred aspects of information seeking, including answers to specific questions and trustworthiness. Accessibility and knowledge were more important aspects than a specific profession, indeed several respondents describe finding a knowledgeable person and then using them as their 'go to' source above all others e.g. pharmacist with dementia knowledge.

The apparent contradictory finding that people feel well informed but also feel that they have not had enough information may point to the struggle to find information actively. It is possible that people are able to find the information by actively seeking it out and educate themselves but find it a struggle when coupled with the stresses of a diagnosis of dementia. It is not clear from these results whether the lack of information relates to active or passive information. It could be that people feel that they need more information provided passively and thus saving them from the struggle to find it. Indeed the results here indicate that those with a close family member or friend with dementia do receive or find information following diagnosis as the longer the time since diagnosis, the better informed participants felt. This indicates that it is not the end result in the information search but the route to reach an

appropriate level of knowledge which influences carer's perceptions of information gathering in dementia.

### 7.4.1 Internet

Contrary to previous research e.g. Fischer *et al.*, (2014), the results show that the ability to access the internet is widespread throughout all ages. However, age related differences were seen in the regularity of internet use and the likelihood of using the internet to look for dementia information. Older internet users accessed the internet less often than their younger counterparts and were less likely to use the internet to find dementia information. The internet is fast becoming a vital part of daily living which is leading to an increase in older people getting 'online' (Wagner, Hassanein and Head, 2010). These results highlight that although older people have the skills and equipment to enable them to use the internet, they are less likely to consider it for information seeking. It is noteworthy that respondents who used the internet more were more likely to feel overwhelmed by the amount of information given and unable to take it in.

The ability to use the internet for information and an opposing dissatisfaction with dementia information in general may show the health culture shift for the 'baby boomer' generation. This generation have previously relied on health professionals for their health information and it is possible that they trust and feel comfortable with this method of obtaining information. The results suggest that they have the basic skills to use online sources but are more comfortable with professional sources and would like to continue to find information in this way.

Individuals accessing the internet need to rely on their own judgement in assessing the trustworthiness of information from the internet and respondents here indicated that they felt that the quality of information from internet sources was good or very good. Internet sources also scored less negatively than healthcare professionals for both trust and accessibility. However, research by Anderson et al. (2009) found that when online sources in the United States were empirically tested they were found to be extremely variable both in their quality and usability. In this study charities and

government run websites are those most commonly used to access dementia information, which perhaps indicates that when internet users seek information from websites that they believe come from trusted sources. There was no correlation between age, perceived trust of internet sources and the number of websites used.

Respondents here stated that they trusted the internet and found the information credible, this is in disagreement with Sweet et al, (2013) who found that the internet was not perceived as a reputable source due to its breadth and difficulty judging the quality of its content. Differences in the methodologies may explain these differing findings. One possible explanation for these differences comes from a study by Pecchioni & Sparks (2007) who found that family members of those with cancer found the internet more useful than the patients themselves this, they hypothesised, could be due to family members having less access to health professionals and therefore needing to seek information from elsewhere. The study by Sweet et al. (2013) used participants who had MS themselves, where the present study recruited family members and friends of those with dementia.

Issues relating to difficulties with obtaining information from health professionals by family and friends is highlighted by open responses indicating that the internet was very likely to be used as a source of information as it can be accessed in private without a family member with dementia being present to question the search for information. This is important in dementia as there is often a reluctance by those in the early stages to accept the diagnosis (Macquarrie, 2002). Family members of individuals with cancer found similar issues due to family members being unlikely to attend doctor appointments or be able to ask medical staff questions directly due to confidentiality (Pecchioni and Sparks, 2007). In this way the internet offers an information lifeline to those who have a family member who is affected.

## **7.4.2 Media complementarity**

What appears from the data is a need for integrated multiple sources of dementia information which supports findings from Suhonen et al. (2015), however in the present study age and educational level had less influence over perceived levels of



knowledge about dementia. PwD all have some contact with healthcare professionals, who they expect to be knowledgeable about dementia and be able to signpost them to appropriate support and services. The internet is a popular source of information but for many does not replace the need for face-to-face advice from professionals.

The internet was not the first choice for information on any of the given topics. Health and social care professionals were approached before the internet for information on medication, memory and other symptoms. Therefore the internet, as a new source of information, is not taking the place of more traditional sources but rather used as a supplemental information source used when relational sources cannot be accessed. This supports the findings of Lu and Yuan (2011), that although people would prefer information directly from another person but they are forced to use another source due to lack of appropriate people to ask. This could account for the voiced unhappiness with information provision even though the information was then accessed but via non-relational sources such as the internet.

Lu and Yuan (2011) also discuss a further concept which may account for the disparity between the internet being the most used information source, but not the preferred information source for the participants. They found that when information need is high i.e. a large difference between current knowledge and uncertainty and level of knowledge required for an individual to feel that a query has been answered, people are more likely to seek out a relational information source and put more value on the quality, rather than the accessibility of the source. Yet in health and social care there is little that individuals can do to access the inaccessible and therefore must then rely on other sources of information.

Due to its greater accessibility, the internet was used prior to appointments with health care professionals to enable respondents to achieve more in their allotted time by being better prepared and informed. This is in agreement with studies looking at information seeking following a cancer diagnosis (Pecchioni and Sparks, 2007). This relationship is bidirectional as other studies have shown that family members also use online sources to clarify terms used by clinicians (Nagler *et al.*, 2010).

More research is needed into the interplay between sources of information. This research lends weight to the suggestions by Harland & Bath (2008), that carers of those with dementia may use differing information sources for different types of information and support. Significant others of PwD turn to family and friends first for emotional support which is perhaps expected. What is unclear is whether this choice is related to the severity of the dementia faced, does information need and therefore their choice of information source change as the condition progresses. Progression of dementia symptoms means greater time spend in caring tasks, which then impacts negatively on time available for information seeking but may increase the information need of the carer. Does this mean the time needed to access a source of information becomes more influential in an individual's choice to use it?

### **7.4.3 Socioeconomic aspects**

The finding that there is a link between an individual's ability to take in all of the information offered to them and the highest level of education they have achieved is perhaps not unexpected. Yet, in this study there is no corresponding link to active searching behaviour or perceived quality, accessibility or comprehension of different information sources. This supports the motivation-contingency model which postulates that a diagnosis of a condition (in this case dementia) mitigates for differences in education levels and health literacy as the diagnosis becomes a motivating factor in information seeking (Kwak, 1999; Lee *et al.*, 2012).

### **7.4.4 Tacit, explicit or embedded knowledge**

Tacit and explicit knowledge sit on a continuum. Participants express a desire for both tacit and explicit knowledge. National guidelines regarding information provision by healthcare professionals focus on the provision of information regarding treatment, services and disease progression (National Institute for Health and Care Excellence, 2010). These topics lie at the explicit end of the information continuum and therefore, information provision following diagnosis (when information need is at its greatest) may not be providing suitable levels of tacit knowledge to meet the expectations of PwD and their relatives and friends.

Embedded knowledge is that which is intrinsic to the understanding of systems and processes (Orr and Jain, 2015). In the case of long term conditions such as dementia this is represented by knowing how healthcare systems work and the process of obtaining help from the correct service. Interestingly the open responses here frequently talk about GPs and health professionals not being aware of services and referral processes which both relate to embedded rather than explicit or tacit knowledge. In the UK, healthcare is divided in geographical health trusts as well as mental and primary care trusts. Support services can be provided by NHS or social services or charities. Given that information services differ between localities and for differing condition, it could be suggested that rather than embedded knowledge, referral routes and optimal access to information services and other professionals relies on knowledge sitting towards the tacit end of the spectrum.

#### **7.4.5 Individualised information**

Participants here also back up another common finding in information literature the concept that one size doesn't fit all. This was commonly mentioned in responses asking for the ideal information provision. Previous reviews of information services found the same (Koenig, Steiner and Pierce, 2011; Washington *et al.*, 2011; Suhonen *et al.*, 2015). However, there is real difficulty in providing cost effective yet individualised information. Face-to-face contact perhaps offers the most straightforward option, where carers can ask individual questions and therefore tailor the information they are seeking. Relational professional contact comes at a financial cost for example the cost of a GP face-to-face consultation is £3.90 per minute. The average GP appointment time in the UK is 9.22minutes which means the average UK GP appointment is £36 (Curtis and Burns, 2016). However the cost of a GP telephone triage appointment is less than half the costs at £14.40. A freedom of information request reveals that the costs of a visit to NHS Choices (the NHS online information platform) costs 1.8 pence.

Secondly, in order to provide personalised information it is first necessary to accurately assess individual information need, a finding that was voiced by Koenig et

al. (2011) and Suhonen et al. (2015), however there remains no effective way for health care professionals to quickly and effectively assess information preferences and need. Currently, no validated, reliable or practical assessment techniques are being utilised for this population.

The internet and printed material does not take into account the health literacy of the individual (health literacy refers to the ability of an individual to obtain, understand and use information about health). This could account for some of the desire for face to face information which allows the information seeker to ask questions in order to confirm their own understanding of the topic being discussed.

#### **7.4.6 Limitations**

It is worth noting when looking at the data here that the results may not be as clear as they first represent. Dementia charities are a widely used source of information about dementia but the charities themselves make use of a variety of information platforms to provide information, therefore it is reasonable to consider that scores relating to internet use, support groups, telephone helplines and dementia advisors are all connected.

Stringent efforts were made to recruit participants from a wide range of places including JDR and locally placed advertisements. However, whilst postal and telephone questionnaires were offered no participant requested a telephone call and only 14 replies (6.6%) were received via post. It is unclear whether this bias towards online replies is a representation of internet use or shows recruitment bias towards those who use online sources. Although efforts were made to advertise and provide the survey by other means the results may still be biased.

Whilst the survey asked participants about the length of time since dementia diagnosis of their friend or family member, the severity of their dementia symptoms was not addressed. There is a possibility that the sources of information used correlates to the severity of dementia symptoms faced as this may also impact on the amount of time

available to carers to spend seeking information and the breadth of information required.

## 7.5 Conclusion

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These results highlight that good quality and trustworthy internet sources are being widely used by people with family members or friends with dementia, however there remains an important need for health professionals to be well informed and accessible to provide good quality dementia information as this may influence how well-informed carers feel over the whole disease progression.

All sources of information provide advice and information for people caring for a relative or friend with dementia but they are not equally useful to this population. The main determinants for information source use are accessibility and the ability of the source to address specific individualised queries. However this data represents a dichotomy between what sources of information that are being used and where family and friends of individuals with dementia would most like their information to come from.

The selection of the internet as the most used form of information is not due to its ability to provide quality or individualised information, it is rather 'any port in a storm' where, in the absence of the preferred source of information (dementia specific health care professionals) the internet represents a quick, accessible resource that can provide some answers.

Two questions arise from this: how can healthcare professionals in the modern healthcare systems be the information source wanted by the family and friends of those with dementia? Or can the internet or other digital platform ever replicate face-to-face meetings with specialist healthcare professionals but in a more accessible way? The answer may lie in a compromise between the two and improved joined-up information sources.

The initial home adaptation study (Chapter 5), found that people with dementia and their carers are not given enough information about adapting their home for dementia and here the data indicates that the preferred source for seeking information is from trusted health and social care professionals. Therefore, a study was then designed to examine the extent of knowledge regarding home adaptation for dementia amongst practitioners and how they then disseminate this knowledge to service users.

## 8 Home adaptation for dementia: Information provision by practitioners in the UK

## 8.1 Introduction

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This chapter describes the third and final research study undertaken as part of this thesis. The home adaptation study described in Chapter 5 found that PwD and their carers were not adapting their homes following a diagnosis of dementia. This appears to be due to a lack of knowledge about how the physical environment can be designed to assist with living well with dementia. The subsequent study (Chapter 7) found that whilst people looking for dementia information use the internet, the preferred method by which to obtain information is from a knowledgeable, accessible practitioner. Therefore, the current study aims to discover what healthcare and charity practitioners know about home adaptation and what advice or information they routinely give.

The previous Home Adaptation study (Chapter 5), found that PwD rated being able to remain living in their own homes as very important. This can be achieved with the right level of social support and if they live in a physical environment that meets their needs (The Alzheimer's Society, 2011; Alzheimer's Society, 2014). Two thirds of PwD live in their own homes in the community (Andrews and Molyneux 2012). One way of meeting challenges felt by PwD, living at home is the adaptation of the physical environment (Pollock and Fuggle 2013). Traditionally, housing adaptations in dementia have focussed predominantly on safety, avoiding falls and promoting safe transfers. More recent research has highlighted specific design factors that can increase quality of life, promote carer ease and reduce impairment (van Hoof *et al.*, 2013). It is these which are of most interest to this research.

The Dementia Friendly Housing Charter released by the Alzheimer's Society in 2017 aims to improve the wellbeing of PwD by informing housing agencies and professionals how they can assist people with dementia. The charter outlines the need for PwD and their carers who are living in the community to have access to home adaptation information and services in order to maintain their independence and quality of life (Moore *et al.*, 2017). However, although the charter describes which housing sectors and professions could carry out adaptations, it stops short of advising how PwD are



referred to these services following diagnosis. This is especially relevant given that 76% of people over 65 years of age in the UK are owner occupiers and therefore are unlikely to have other contact with housing services (Department for Communities and Local Government, 2015).

In the National Institute for Health and Care Excellence (NICE) quality standard for independence and wellbeing in dementia, quality statement 7 refers to the design and adaptation of housing and states that there should be: *“Evidence of local arrangements to ensure that staff are trained to recognise when adaptations to housing can help meet the specific needs of people with dementia.”* (National Institute for Health and Care Excellence, 2013). The staff referred to by this quality guideline are those within organisations providing care and support to people with dementia.

Furthermore, the scope of the NICE clinical guidelines for supporting PwD and their carers in health and social care includes: *“all health and social care staff involved in the help, treatment and care of PwD and their families and carers.”* (National Institute for Health and Care Excellence 2016. p42). The guideline addresses the promotion of independence of PwD and states that care plans should always include environmental modifications and assistive technology and individuals should receive advice from either an OT or clinical psychologist.

However, some services such as occupational therapy and social services tend to be accessed during or following periods of crisis (Steultjens *et al.*, 2004). There is little evidence to suggest which sources of advice regarding housing and home adaptation are provided in the period following a dementia diagnosis, earlier in the disease process, aimed at preventing health and care crises such as an acute admission to hospital or social care breakdown.

There is evidence that suggests PwD and their carers value advice regarding ways to manage behavioural symptoms rather than physical ones (Koenig, Steiner and Pierce, 2011). Previous research shows that home adaptations are predominantly used to address physical limitations (Damme and Ray-Degges 2016; Gabriel *et al.* 2015; Marquardt *et al.* 2011; Allen *et al.* 2017). Furthermore, the NICE Quality standard

which addresses support in health and social care (as shown in Appendix 1), states that the physical environment should be assessed for all PwD showing non-cognitive symptoms. Therefore, there is a disparity between the desire to know ways to address behavioural symptoms, assessment by health and social care professionals and the use of home adaptation as a modality to achieve this. One possible explanation for this is the perceived lack of knowledge reported by PwD and their carers (Chapter 5). Receiving face-to-face advice and support from health and social care professionals, specialist dementia advisors and attending dementia specific support groups are common ways to receive education about coping with dementia (Ipsos Mori, 2016; Killen *et al.*, 2016). Yet, little is known about the current provision of home adaptation guidance by those delivering face to face advice to PwD and their carers. A paucity of knowledge regarding home adaptation amongst professionals providing advice and information could affect its uptake in the homes of PwD.

### **8.1.1 General Practitioner Knowledge**

General practitioners (GPs) are present on the frontline of patient – healthcare interaction and therefore have an important role to play in the diagnosis and management of dementia in the community. They can be seen as gatekeepers to a raft of dementia care and services (Sivananthan, Puyat and McGrail, 2013). An Australian study by Millard (2008) interviewed twenty PwD and family carers of people with dementia. They found that other health professionals who had a more specialised role in dementia often attributed participants' difficulties getting support from their GP to their lack of specialist knowledge. They also found that GPs who were more responsive to carers needs received more positive feedback from participants. This is also supported by data in the Information Sources study (Chapter 7), which found that GPs who were perceived as more easily accessible were also perceived as providing better quality advice.

A descriptive by Sutcliffe *et al.* (2016) found general practitioners working within community mental health services were felt to have a generalised lack of understanding of issues relating to dementia care, especially within secondary (acute)

care settings which impacts on the quality of care and wellbeing of service users with dementia. The mixed group of hospital and community healthcare staff (n=23) who participated in the two focus groups, also felt that dementia services would benefit from dementia specific rapid response teams (Sutcliffe *et al.*, 2016).

### 8.1.2 Occupational Therapists

Occupational Therapy (OT) is an allied health profession which is concerned with the promotion of human occupation to promote health and wellbeing (Wong and Leland, 2016). OTs promote practical skills to aid independence and quality of life. OTs are responsible for a significant amount of living aid equipment which is loaned to individuals through equipment loan services (McGrath and O'Callaghan, 2014).

In a survey of OTs in Australia (n=134), Bennett *et al.* (2011) found that environmental modifications were the most frequently used treatment modality for people with dementia, followed by the use of assistive technology. Environmental modification was also the most common reason for OTs to receive a referral from other health professionals, to see a patient with dementia. Over 51% of respondents had not received any formal dementia training and 35.8% of participants stated that a lack of knowledge created a barrier to delivering interventions to people with dementia. However respondents in the study were not dementia specialists and spent less than 25% of their time treating or assessing people with dementia. The study did not ask participants to specify which environmental modifications were being made and the extent of these.

Occupational therapists gave environmental modification advice in 74.4% of cases when treating people with dementia, more than any other treatment modality. This study, by McGrath and O'Callaghan (2014), of Occupational Therapists (n=47) in Ireland showed that although environmental modification advice was common it was not used in conjunction with follow up support which has been recommended by previous research (Graff *et al.*, 2007; LN, Winter, MP, Hodgson and WW, 2010). Similar to the research by Bennett, Shand and Liddle, (2011), respondents stated that the biggest barrier to translating research evidence into their practice was a lack of time

(McGrath and O'Callaghan 2014). Unfortunately, although OTs provide the most environmental advice, community OT services for dementia can be difficult for other health care services to access for their patients (Sutcliffe *et al.*, 2016).

### 8.1.3 Support Groups

Groups offering social and educational support to people following a diagnosis of dementia have been shown to decrease carer burden and promote well-being and social outcomes (Chien *et al.*, 2011). Past research has concentrated on the types of interaction within the groups, and the effectiveness of different types of groups. Little has been published on the relative effectiveness of differing educational content. Therefore there is a variety of different content from group to group.

Roberts and Silverio (2009) evaluated an education programme in America which offered four sessions to those newly diagnosed with Alzheimer's disease and their significant others. They found that even through as little as four; two hour long sessions there were significant improvements in health behaviours and enrolling in further support networks. However no change was shown in ability to cope with the disease through psychological adjustment, reduced caregiver strain or Alzheimer's disease knowledge. Although the authors listed the general topics included in the education element of the group it is unclear whether specific home adaptation advice was included (Roberts and Silverio 2009). This was also true of a study by Wang and Chien (2011), who found significant positive effects on hospitalisation and carer burden of a family support group when compared to a control cohort without support group input. Here the input was of longer duration and consisted of bi-weekly two hour meetings over a 6 month period. However, once again, no specific breakdown of the educational content of the groups was given (Wang and Chien 2011).

One small pilot study relating to a café group for PwD and individuals with learning difficulties provided information about the physical and sensory environment and dementia during the 'carers talks' section (Kiddle *et al.*, 2016). Feedback following these sessions found the advice to be helpful to participants. However, there are several limitations within the methodology, including that the participant group was

extremely small with only 3 participants having a dementia diagnosis. None of the participants lived in their own or family home which would make the modification of the home environment more difficult to complete and perhaps more importantly no empirical data was gathered for the education portion of the sessions.

#### **8.1.4 Information Seeking and learning for practitioners**

Healthcare professionals must complete ongoing learning to maintain their fitness to practice. This is known as Continuing Professional Development (CPD) (Phillipson *et al.*, 2016).

Joynes et al. (2017) published a qualitative study exploring where and how generic informal workplace learning takes place within GP practices. Using focus groups made up of GPs, practice nurses, specialist nurses, managerial and administrative staff (n=27) they found that learning was triggered by different types of event: Specific patient needs, new or novel problems, being exposed to other professionals practices and lastly changes in policy. These learning triggers were seen as opportunistic and limited by the time available. The recurring link between the learning triggers was the importance of peer support and learning, knowing which team members may have specific experience and using knowledge and expertise already present within the group. However they also found that where some teams of staff regularly met in groups, others did not have a well-defined structure of peer support.

#### **8.1.5 Summary**

In summary, although previous research has found that adapting the home environment can mitigate the behavioural, cognitive and physical impairments of dementia, its use is predominantly limited to adaptations that assist with physical symptoms. This is, at least in part, due to a lack of awareness and access to information regarding home adaptation techniques by those living with dementia. Support and advice about adapting the home environment for those living with dementia is recommended by the national NICE guidelines (Appendix G) and should be provided

by a number of different individuals and services but it is not clear what, if any, home adaptation education these providers are delivering.

## 8.2 Aims

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The aim of this study is to investigate the knowledge and provision of home adaptation for dementia information by support services and individuals.

### 8.2.1 Research Questions

- Where do individuals offering face-to-face support to PwD and their carers access knowledge and / or receive training about home adaptation for dementia?
- Which services and /or practitioner roles currently offer advice about modifying the home environment to PwD and their carers?
- What is the extent of, and method of delivery for, home adaptation advice offered?

## 8.3 Methods

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### 8.3.1 Recruitment

Purposive sampling was used and participants recruited via posts on social media, calls through online forums from professional bodies such as College of Occupational Therapists and Royal College of Nursing following the receipt of appropriate permissions. Charity groups such as the Carers Association and Alzheimer's Society were approached in order to recruit those running dementia support groups. Snowball sampling was also implemented from those already participating.

Individuals interested in taking part were signposted to the questionnaire URL which also contains the Participant Information Leaflet and Consent Form.

### **8.3.1.1 Participants**

The sample included dementia practitioners (defined as anyone who has face-to face meetings with people who live at home with dementia and provides advice or education). This included health professionals, social services professionals, charity workers and dementia advisors.

#### *8.3.1.1.1 Inclusion criteria*

- Provides face-to-face advice and support to PwD or their carers including individual treatment or groups.
- Works in a professional or official voluntary capacity for a recognised charity or health and social care provider.
- Works with PwD who live at home.

#### *8.3.1.1.2 Exclusion criteria*

- Does not work specifically with PwD or their carers.
- Works only with those in residential care.
- Operates in a purely unofficial capacity e.g. as a peer or friend of someone with dementia.

### **8.3.2 Study Type**

A study-specific questionnaire was developed and used to gather information.

#### **8.3.2.1 Questionnaire development**

The questionnaire included a combination of closed and open questions. The questionnaire underwent a process of design including the formation of questions stemming from previous literature and interviews with PwD and their carers in the previous Home adaptation study conducted by the researcher (Chapter 5). The structure and derivation of the questionnaire, including the links between the research questions and questions within the survey itself can be seen in Appendix H.

The second half of the survey took the form of vignettes. These vignettes were short stories or snapshots involving hypothetical people and challenges due to dementia

that practitioners may be asked for advice about (Finch, 1987). Vignettes were used because they have the ability to provide rich data and provide a more interesting platform for busy practitioners to engage with the research (Spalding and Phillips, 2007). Survey participants were asked to respond to the issues posed in the vignettes and outline what their professional actions would be. Research vignettes have been shown to be a useful approach to encourage reflexivity in health professionals and encourage a holistic response to the survey questions. (Spalding and Phillips 2007; Peabody et al. 2004). They have also been used as a measure of clinician knowledge and in the training of medical professionals (Peabody *et al.*, 2004).

In line with the structure proposed by (Barter and Renold, 2000). The vignettes were designed to provide enough detail for respondents to understand the context of the situation but with some ambiguity in order to 'draw' out information regarding judgement decisions made by participants, as described by Barter and Renold (2000). The scenarios were derived from two sources. First, the experiences of participants in a previous study (Chapter 5) and their experiences of home adaptation for dementia. Second, the extensive clinical experience of the researcher working in the homes of PwD and their carers. The five vignettes use scenarios which include issues relating to physical, cognitive and behavioural challenges concerning living with dementia (as shown in Table 13). All of the scenarios contain a social element due to aspects of carer input, and all of the individuals depicted live in the community.

***Table 22. Vignette scenarios and the symptoms they address***

### **8.3.2.2 Questionnaire pilot**

The questionnaire was also piloted by a group of healthcare professionals with experience of working with PwD who completed the questionnaire and provided feedback on the survey structure and content. Following pilot feedback modifications were made. During the piloting phase, feedback was provided on how realistic the situations portrayed by the vignettes were.



<p><b>Vignette 1: Physical</b></p> <p>John is a 70 year old man diagnosed with Alzheimer's disease and lives with his wife in a house. He is independently mobile but has fallen twice in the last two months whilst wandering during the night. His wife Anne is also concerned about his general lack of sleep.</p>
<p><b>Vignette 2: Cognitive</b></p> <p>Janet is a 54 year old woman with a diagnosis of frontotemporal dementia and who lives alone. She wants to maintain her ability to make hot drinks and prepare simple meals. Her family have voiced concerns about whether she is eating and drinking enough.</p>
<p><b>Vignette 3: Physical and cognitive</b></p> <p>Mary is a 78 year old woman and is the main carer for her husband George, who is 82 and has a diagnosis of Vascular Dementia. She says that she is finding it stressful to assist her husband with personal care and toileting. They live in a bungalow and he is independently mobile but requires assistance to find and use the bathroom and sequence personal care tasks.</p>
<p><b>Vignette 4: Cognitive</b></p> <p>Bill is an 85 year old gentleman who has a diagnosis of Alzheimer's disease who now lives with his son and struggles to use the front door and therefore has a tendency to leave it open. This has lead his son to worry about safety and also frustration in his father's inability to learn to operate the door.</p>
<p><b>Vignette 5: Behavioural</b></p> <p>David is a 72 year old gentleman who is carer for his partner, Joyce (71) who has lewy body dementia. She is agitated and has episodes of aggression during the day and her partner is finding her behaviour increasingly challenging but is determined that they both remain at home.</p>

*Table 22 Vignette scenarios and the symptoms they assess*

### 8.3.3 Data collection

The questionnaire (including vignettes) was administered via the Bristol Online Surveys tool (run by jisc.ac.uk).

### 8.3.4 Data analysis

Frequency statistics for the demographic information such as age, role, length of time spent working with PwD and area of work were calculated and used to explore the sample of participants.

#### 8.3.4.1 Closed questions

For the simple yes/no questions, frequency data was calculated using IBM SPSS 22 software. One Likert response question was used: 10.a. *Following a recommendation to make a specific adaptation, how likely is it that an individual with dementia or their carer will carry out the recommended changes?*

#### 8.3.4.2 Open questions

For the open questions (as shown in Appendix H) a simple thematic analysis was used. For question 4.c. *'Briefly describe the main purpose of your service/role?'*, Replies were separated into different roles and specialisms based on the detail within the reply and researcher knowledge. The data from question 5.c.i: *'Please could you specify how your practice changed?'*, was read for meaning and then reread and common themes within the data were drawn out.

Questions relating to the perceptions of respondents as to how their clients feel about making changes to their homes was analysed using NVIVO 11 software. The data was grouped into two broad categories, positive perception and negative perception. Following initial analysis, a third category was added; 'Influenced by the understanding of the individual'. These broad categories were then further analysed for common themes and ideas.

#### 8.3.4.3 Vignettes

The vignette data were analysed via NVIVO 11 software. Frequencies of different home adaptations were recorded for each of the five vignettes. These adaptations were then grouped as Additive, Behavioural, Subtractive or Transformative in nature as previously described by Pynoos et al. (2012). An extra category of *technological* was added for the purposes of this study due to the recent rise in the use of both assistive

technology and telecare. This technology does not sit appropriately with any of the four traditional groups of home adaptation and therefore it was decided to analyse this adaptations separately.

The types of recommendations and advice detailed by respondents was then compared to role title and the service description given, in order to identify commonality between roles and information provision.

Data regarding further signposting and referrals were also coded for each vignette and cross referenced to each role.

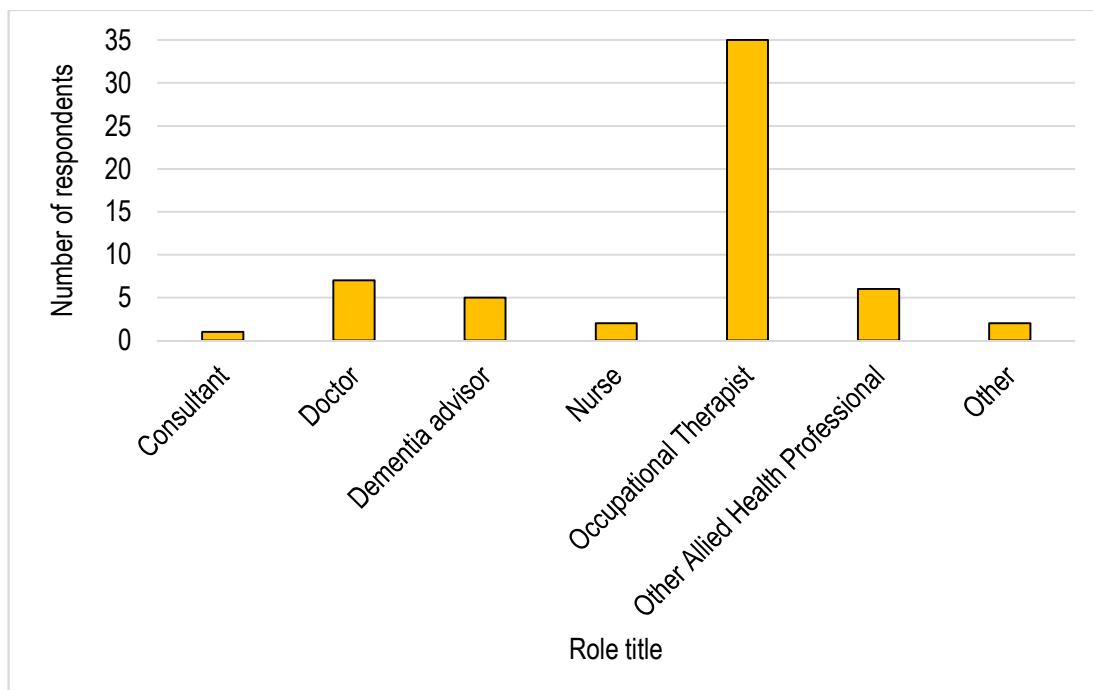
## **8.4 Results**

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A total of 58 questionnaire responses were received between 29<sup>th</sup> November 2016 and 1<sup>st</sup> September 2017 due to the strict time constraints on the study. A total of 637 people accessed the first page of the survey but did not start to answer the questions. A further 69 people began the survey but did not complete it.

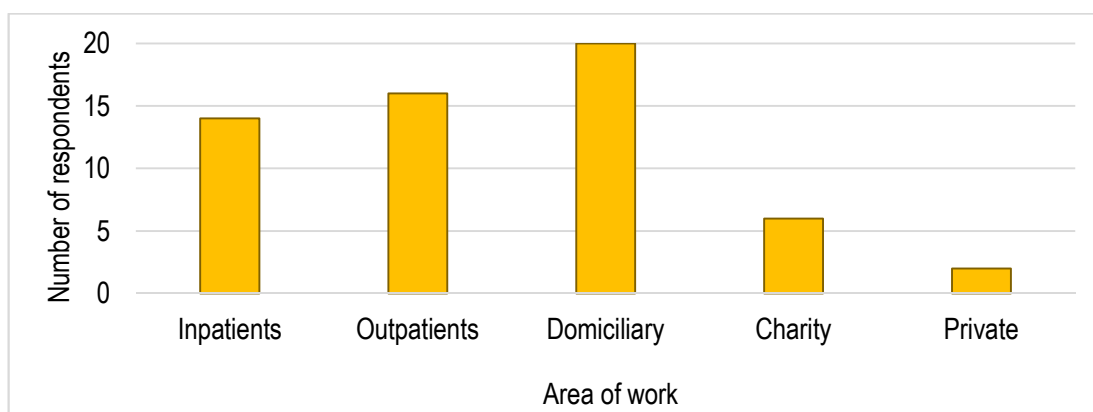
### **8.4.1 Characteristics of the sample**

The most common role was an Occupational Therapist (n=35) followed by Doctor (n=7) as shown in Figure 27. Two respondents who marked themselves as 'other', one being a dementia support worker and the other was a consultant psychiatrist who, for the purposes of data analysis was placed in the consultant group.



*Figure 27. Roles of practitioner participants*

The most common area for participants to work in was domiciliary (n=20) within which clients or service users are seen within their own home environment Figure 28. Respondents worked in five different types of setting with the most common being domiciliary (n=20), followed by outpatient (n=16) and inpatient (n=14). Smaller numbers worked for charities (n=6) and in the private sector (n=2).



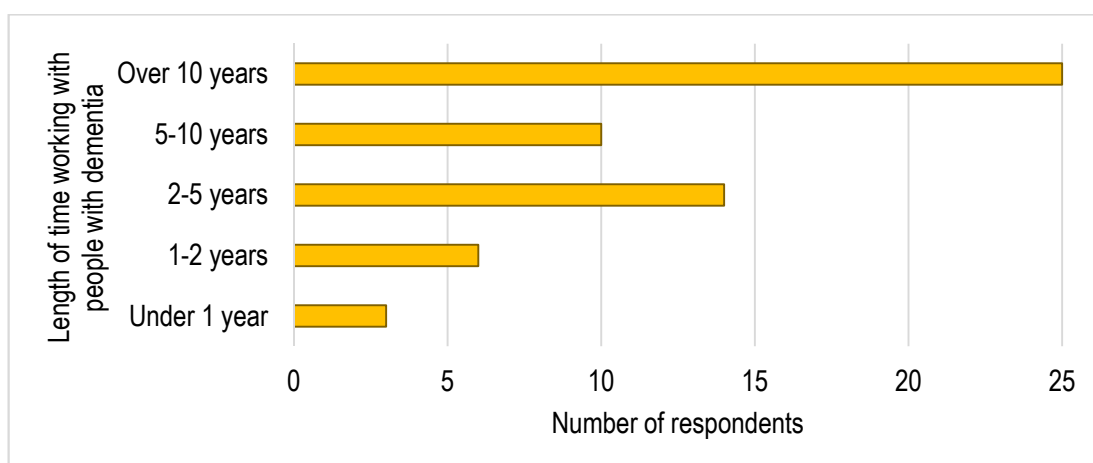
*Figure 28. Area of work*

The age of participants were positively skewed towards age groups between 25 and 54 as would be expected for a sample of adults who are employed, see Table 3.

Age Group	Number of Respondents
Under 25	3
25-34	12
35-44	15
45-54	16
55-64	8
65-74	2
75+	1
Missing	1

*Table 23. Participants by age group*

Figure 29 shows that the most common length of time in a role giving advice to PwD and their carers was over ten years (n=25) and the least common was under one year (n=3).

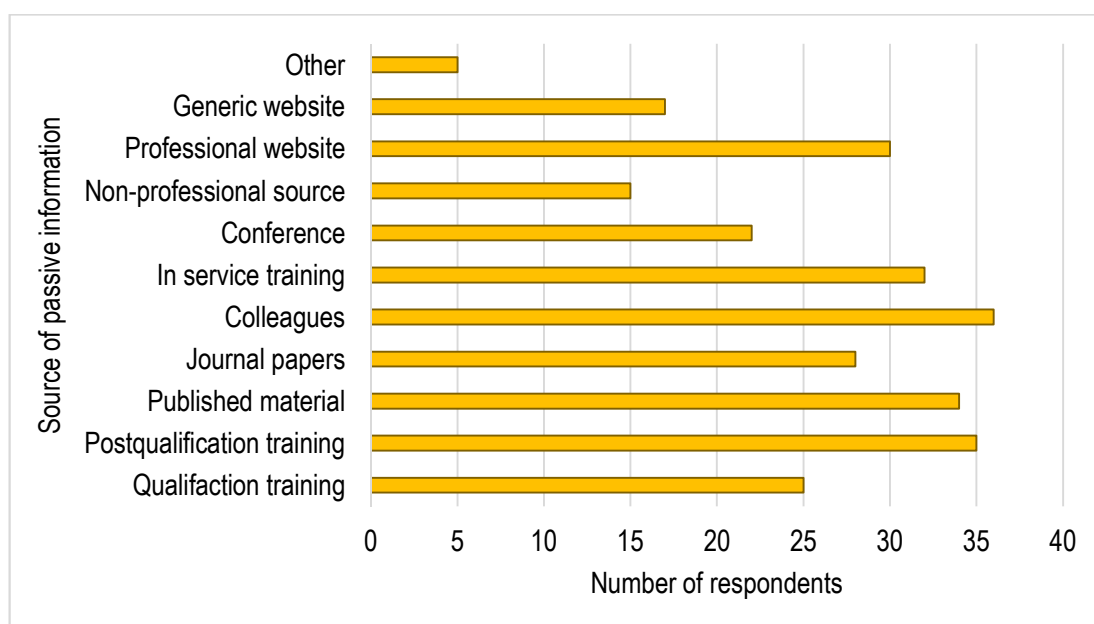


*Figure 29. Length of time in a role giving advice to PwD or their carers*

#### 8.4.2 How home adaptation knowledge has been obtained

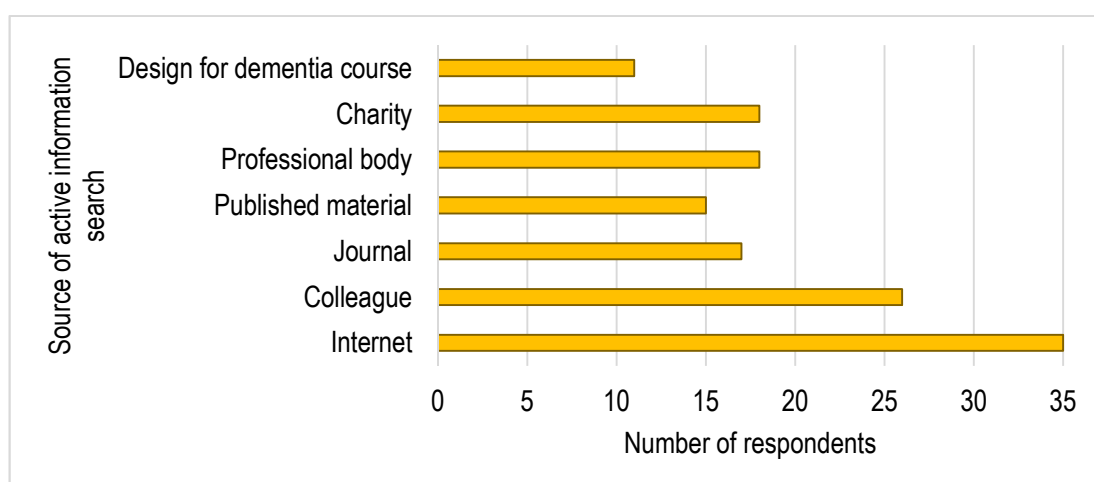
In total, 91% (n=53) of the professionals had received passive information about modifying the physical environment for dementia. The receipt of this passive information lead to 77% (n=41) of these practitioners to seek out further information and 85% (n=45) to then go on to change their practice. The most common source from which to receive passive information about home adaptation for dementia was other

colleagues (n=36), followed by attending post-qualification training (n=35), as shown in Figure 30.



*Figure 30. Sources of passive information about modifying the physical environment in dementia*

When asked about active information searching about design and the physical environment for dementia, 74% (n=43) responded that they had sought information in this way. For an active search (Figure 31), the internet was the most commonly used source (n=35) with colleagues now the second most preferred option (n=26).



*Figure 31. Sources of information used for active searching*

The most common instigating factor for respondents' search for information was a desire to improve knowledge (n=34) followed by the need to address issues linked to a specific client (n=25) and to follow up information from elsewhere (n=23).

Following the receipt of information about the adaption of the physical environment in dementia 78% (n=45) then went on to change their practice to reflect their new knowledge. The breakdown of number of practitioners making changes to their practice varied between different roles as shown in Table 24. Percentage changing practice after gaining knowledge about the home environment and dementia (Table 15). This highlights that although 86% of GPs had seen or searched for information regarding how the physical environment can be adapted for people with dementia, only 29% had then gone on to change their practice.

<b>Job Role</b>	<b>Percentage changing practice following increased knowledge of the physical environment in dementia</b>
Dementia Advisor	100
Consultant	100
Nurse	50
Occupational Therapist	86
GP	29
Other AHP	83

*Table 24. Percentage changing practice after gaining knowledge about the home environment and dementia*

A summary of changes made by practitioners can be seen in Table 25, the most frequent of which was an improved ability to discuss the impact of the physical environment with service users or patients.

<b>Change made to practice</b>	<b>Number of participants</b>
Improved ability to discuss physical environment in dementia with stakeholders	18
Improved person centred care	11
Increased awareness of impact of perceptual issues relating to colour and decor	8
Cautious about over prescription of equipment	6
Improved referral skills	4
Increased awareness of own practice	4
Improved evidence based practice	3
Consider how adaptations and assistive technology will be monitored	2

*Table 25. How practitioners changed their practice after finding information about the physical environment and dementia*

Participants were also asked what they felt was their level of knowledge about the physical environment and living with dementia and then how they felt about their level of knowledge. Over a quarter, 25.9% (n=15) of participants felt that they should know



more about the physical environment and dementia for their current role and nearly half, 46.6% (n=27) felt that their knowledge was appropriate for their role.

A positive correlation was seen between the number of active information sources used and participants' perceptions of their own knowledge (Spearman's rho  $r = 0.304$   $p > 0.003$ ).

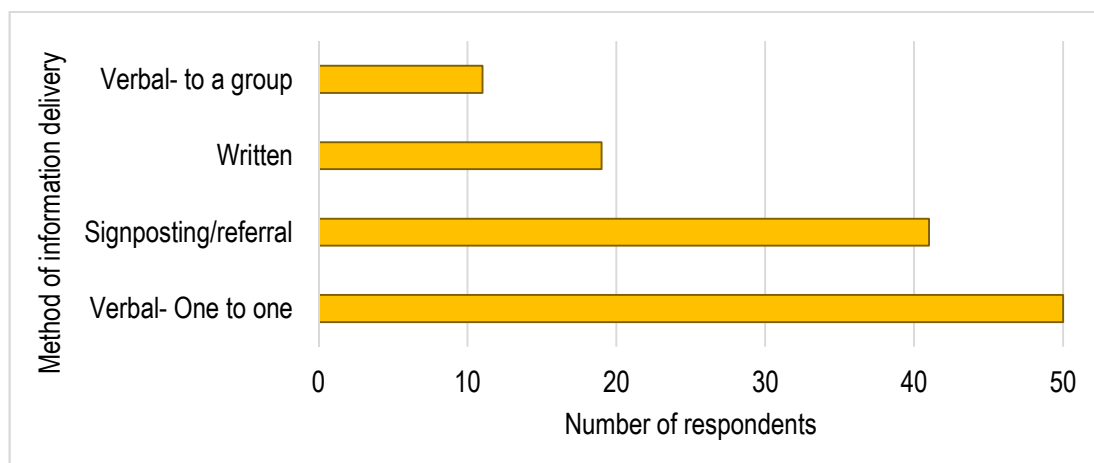
	No Interest in topic	I feel that I should know more for my role	My level of knowledge is commensurate with my role	The topic interests me and I would like to know more	Total	%
No knowledge	0	2	0	1	3	5.2
Superficial knowledge	0	5	3	3	11	19.0
Moderate Knowledge	0	5	11	7	23	39.7
Good Knowledge	0	3	8	5	16	27.6
Excellent Knowledge	0	0	5	0	5	8.6
Total	0	15	27	16	58	
%	0	25.9	46.6	27.6		

*Table 26. Level of Knowledge and feelings of knowledge of home adaptation in dementia by practitioners*

### 8.4.3 How home adaptation knowledge is provided

General advice regarding how making changes to the home environment was given by 88% (n=51) of respondents. In contrast, specific adaptation to a client's home were recommended by 81% (n=47) of practitioners. The most common motivator for the provision of this information was as a response to an assessment of the client or clinical judgement of the respondent (n=46). Only seven respondents indicated that this advice was given to all as part of a standard service provision. Figure 32 shows the methods of home adaptation advice delivery.

The most common form of delivery was via face to face verbal communication (n=50) and conversely the least used was to provide information verbally to a group (n=11). Of the seven people who do not give out general information about the home environment, were from five different job roles (Dementia advisor, GP, Dementia specialist nurse, OT and one physiotherapist) six felt that this information should fall within their role.



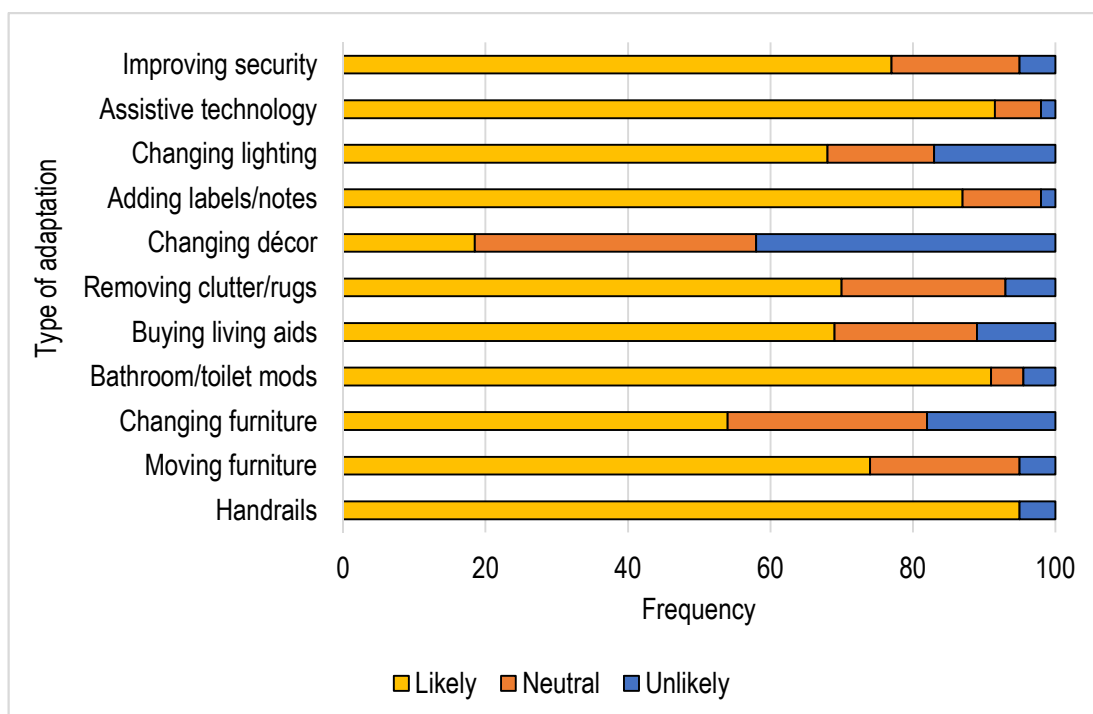
*Figure 32. Methods of delivery of home adaptation for dementia advice by practitioner*

#### **8.4.3.1 The types of recommendations and equipment provided by service**

Over half, 69% (n=40) of respondents worked within services which provided equipment for PwD and their carers. Out of these, the most common equipment provided were those to assist with physical impairment; hand rails (n=34), mobility aids (n=32), manual handling equipment (n=31) and height adjustable beds (n=26). Equipment to assist with cognitive challenges, for example Assistive Technology (n=25) and signs/labels (n=25), were provided by fewer of the services in which participants worked.

Participants showed largely positive perceptions regarding how likely PwD and their carers are to complete the recommendations made (Figure 32). The most likely to be completed or adopted were adding handrails (95% positive), assistive technology

(91.5% positive) and bathroom and toilet modifications (91%). The least likely advice to be carried out was making changes to décor which was seen as unlikely (42%) or neither likely or unlikely (39.5%).



*Figure 33. How likely are clients to carry out home adaptation recommendations?*

These findings were reflected in open responses to questions which asked for the perceptions of participants on how PwD and their carers feel about adapting their homes. Whilst participants were keen to explain that there was variation between all individuals, the most prominent theme to come from the data was that the likelihood of completing home adaptations was dependent on the understanding and insight of the client into their condition and safety issues relating to it (n=21). This insight could be held back due to an unwillingness to accept the dementia diagnosis or restricted in the later stages of dementia due to cognitive decline. Participants felt that where carers were involved they were more amenable to home adaptation advice (n=11).

Of the participants who felt that their clients were reluctant to adapt their homes (n=22), 14 felt that this was due to a reluctance to change a familiar environment. Three felt that this was due to the costs of making changes. Three others stated that their clients were happy to have new equipment fitted but would not make adaptation

which changed the décor or layout. E.g. *“I have yet to see individuals follow up on advice regarding the effect of patterns on carpets, curtains, etc.”* (Participant 54)

#### 8.4.4 Vignettes

The responses to the vignettes showed a wide variety of responses. Participants from all the roles represented by respondents offered advice for environmental adaptation in each scenario. Many participants expressed that in a true situation they would assess the situation and client first and then base their advice accordingly.

Vignette	Additive	Subtractive	Behavioural	Transformative	Technological	Total
1	31	14	15	37	78	175
2	25	5	13	4	25	72
3	53	3	3	22	2	81
4	25	0	2	17	55	99
5	3	1	1	15	3	23
<b>Total</b>	137	23	34	95	163	

*Table 27. Types of adaptation described for vignettes*

##### ***Vignette 1: An individual with dementia who had regular falls at night***

Respondents were asked to describe what, if any, adaptations they would recommend in this scenario. Table 27 shows that the most common types of changes that were recommended involved the use of technology (n=78) to provide sensors and alarms which monitor night-time behaviour. The addition of day-night clocks (n=4) and sensor lights (n=14) were other types of assistive technology suggested.

Transformative (n=37) and additive (n=31) adaptations were the most recommended type of adaptations, with behavioural (n=15) and subtractive (n=14) being suggested significantly fewer times. The high levels of transformative changes were caused in part due to lighting changes being suggested on 33 occasions.

##### ***Vignette 2: A woman with frontotemporal dementia who lived alone and wanted to maintain her independence with kitchen tasks***

For this vignette, technology and additive changes remained the most common suggestions (n=25) but here there was an increase in behavioural recommendations (n=13) which focussed around leaving items needed for eating and drinking out as a visual prompt.

***Vignette 3: Exploring advice around wayfinding and maintaining independence with personal care tasks in the bathroom and toilet***

The most common type of adaptation recommended for this scenario was additive (n=53). 65.4% of recommendations, with the provision of equipment to assist with using the toilet and signage to assist with locating the bathroom. Vignette 3 demonstrated the smallest number of technological suggestions 2.5% (n=2) of all the vignettes.

***Vignette 4: Security and use of technology along with carer frustration and interaction***

In contrast to the previous scenario, vignette 3 offered the most technological suggestions for adaptations (n=55) which equates to 55.6% of all recommendations.

***Vignette 5: Challenging behaviour, agitation and aggression in the home environment***

This situation produced the lowest number of environmental adaptations (n=23), the most common type of adaptation was transformative with practitioners recommending the review of patterns and colours in the décor of rooms to reduce environmental stressors.

#### **8.4.4.1 Vignette Summary**

Overall, in the five vignettes the most common recommendation was the addition of signs, labels and instructions (n=83) and adaptation of the lighting (frequency 49). When grouped by service type, there were clear differences between the number of practitioners who did not provide home adaptation advice through the vignette questions (Table 28).

	<b>Crisis / Acute health intervention</b>	<b>Long term disease management</b>	<b>Self-referral / advice services</b>
Number of practitioners in specialism group	26	16	16
Percentage of practitioners providing home adaptation advice over all vignette scenarios	92%	86%	69%

*Table 28. Percentage of practitioners giving advice over all scenarios by service type*

Suggestions for onwards referrals or signposting were diverse. Vignettes 1 and 2 elicited a greater percentage of referrals to health sources than to social support services. Referrals appearing in the 'Other' column (Table 29) were those that could be classified as either social or health, such as telecare or equipment provision services.

<b>Vignette</b>	<b>Total referrals</b>	<b>Health %</b>	<b>Social %</b>	<b>Other %</b>
<b>1</b>	128	64	27	9
<b>2</b>	96	48	41	11
<b>3</b>	94	27	64	9
<b>4</b>	56	25	52	23
<b>5</b>	98	37	62	1

*Table 29. Referrals by vignette number*

## 8.5 Discussion

The three aims of this study were to explore which practitioners who work with PwD and their families, also provide information about adapting the home environment, where do these practitioners access knowledge on the topic of home adaptation for dementia and how they feel about their knowledge. Lastly the study examined the extent of home adaptation advice, and the methods of delivery used by practitioners to pass on their knowledge to clients or service users.

### **8.5.1 Where do individuals offering face-to-face support to PwD and their carers access knowledge and / or receive training about home adaptation for dementia?**

Practitioners are gaining knowledge about the physical environment in dementia from a number of different sources. In line with the NICE quality statement seven, 91% of respondents had received passive information about environmental modification for dementia. Passive information received from colleagues was the most common way to receive information. Conversely, active information was most commonly sought from internet sources, followed by colleagues. This aligns with findings from Lu & Yuan (2011) who found that quality and accessibility are the characteristics which are the most influential to the choice of active information source amongst employees, but relational and non-relational sources were used interchangeably depending on need.

What we are unable to ascertain from the results is the quality or breadth of information received from colleagues, what we can see is that a large proportion of practitioners use both active and passive information to inform and change their practise. This is also an example of good continuing professional development (CPD), where professional skills are continually being developed and reflected upon to maintain and enhance professional competence (Joynes, Kerr and Treasure-Jones, 2017).

Interestingly, increased knowledge regarding home adaptation led some to be more cautious in the provision of equipment that may cause confusion or a cluttered environment. This is a good example of improving individualised care by reflecting on the impact of additions to the homes of people with dementia. Improved person-centred care was also cited as a perceived improvement made to practise following the acquisition of passive and active knowledge. In a similar way others were lead to consider how the adaptations could be monitored to consider how well they are meeting the needs of those for whom they are provided. This shows an improvement in evidence based application of home adaptation which has been shown by previous research to be more effective with ongoing support (Graff *et al.*, 2007; McGrath and

O’Callaghan, 2014) and improved compliance with NICE quality statement 4 (National Institute for Health and Care Excellence, 2010). Perhaps unsurprisingly, there was correlation between practitioners who find information from a number of different sources and their perception of their level of knowledge.

What is more remarkable is that over a quarter of respondents feel that their knowledge of home adaptation falls below that needed for their role. This was across different practitioner roles. This indicates that there is a short-fall in training and provision of this information to practitioners but may also reflect an awareness of the growing significance of dementia due to its increased prevalence. As stated previously (Chapter 1), dementia is a growing problem, mainly due to an ageing population. Government policy and initiatives aim to increase the rate of dementia diagnosis and much publicity has been given to improving care for PwD (Department of Health, 2016). This increase in prevalence means that those working in general medicine and general practise are now treating PwD more frequently. The increased workload and awareness that this produces could lead to practitioners feeling that their knowledge and skills do not align with ongoing service needs.

NICE guidelines make it clear that all health and social care staff who have contact with those with dementia should have training to recognise when home adaptation can be used and that they should ensure that they have housing that meets their needs (National Institute for Health and Care Excellence, 2010, 2013, 2016). It is possible that health professionals feel that their knowledge does not allow them to meet the expectations of guidelines such as this.

### **8.5.2 Which services and /or practitioner roles currently offer advice about modifying the home environment to PwD and their carers?**

Respondents who represented the full range of roles taking part in the study offered home adaptation advice. However there was considerable variation in the levels of advice given and this was not affected by the scope of the service. What was shown



was that, practitioners offering most home adaptation and equipment are those who work within services who become involved at the point of crisis. This means opportunities are missed to provide advice which may prevent crisis. This supports the findings of McGrath & O'Callaghan (2014) who found that service users felt that the emphasis of the healthcare system was to manage crises and met only urgent needs, whilst missing other long term goals.

Nearly all practitioners offered signposting and onward referrals in all situations, however these referrals were diverse, with little consistency and not following a defined pathway. This again points to elements of luck / chance in obtaining advice about adapting the home.

Neither of the nurses participating here offered referrals or signposting to OT, and although they both described their role as providing support and advice for people living with dementia, their breadth of environmental recommendations was limited. Dementia advisors also offered limited advice about the living environment when compared to other health professional such as OTs, GPs and AHPs. Once again, this highlights, how PwD are less likely to receive information about home adaptation prior to the point where they require greater health and social care input, because the services which are responsible for help and support following diagnosis, are also the least likely to provide environmental recommendations.

### **8.5.3 What is the extent of, and method of delivery for, home adaptation advice?**

In the results from the vignettes, we can see that more recommendations are given for problems relating to physical and cognitive symptoms than for challenging behaviours. Once again, this is in agreement with McGrath & O'Callaghan (2014), who found OTs rarely addressed behavioural symptoms, particularly in those with only mild dementia.

The adaptations / advice given in the vignettes cover a wide variety of evidence based ideas but these are spread throughout the whole sample – no one individual, is giving all the advice.

It appears that the amount of home adaptation provided is determined by the individual practitioner rather than their job title, role, experience or service. This would promote issues relating to chance regarding the quality of information discussed in Chapter 7.

There is also evidence of conflicting approaches from different practitioners, for example in vignette 4 some OTs want to conceal doors to prevent wandering while others want to make them easy to use to promote independence. This could stem from differing experiences of people with dementia, or a different understanding of the vignette scenario.

There is a reliance on assistive technology and telecare and these terms were used interchangeably by participants.

#### **8.5.4 Further findings**

Although respondents feel significantly positive towards the likelihood that clients will complete the adaptations and use most of the equipment offered, there is one exception: changing décor / colours which was felt to be unlikely to be completed.

Practitioners have mixed perceptions of whether PwD and their carers were likely to carry out the recommendations they make – they state that if people have not yet come to terms with their / or their loved one's diagnosis then they were unlikely to make changes. However they also felt that people with more severe dementia had less insight and encouraging changes to the home became more stressful and difficult. This is the OHAP which was found in home adaptation study (Chapter 5). It is also the same phase where crisis point is less likely due to symptoms being less profound. Therefore, the OHAP occurs at the point that home adaptation advice is least likely to be given.

### 8.5.5 Limitations to the current study

The results from this study are likely to be affected by the small sample size (n=58) and the weighting of participants towards Occupational therapists (n=35). Despite stringent efforts by the researcher to recruit participants over a number of months and through a variety of professional and charity groups, uptake remained low and far short of the one hundred plus participants aimed for at the outset. Metrics provided by Bristol Online Surveys shows that 637 people accessed the introduction to the study but then did not go on to complete the survey. This could be for several reasons; the participant information leaflet was too lengthy and therefore busy practitioners did not feel that they had time to read all of the information offered, or perhaps practitioners who were not dementia specialists did not think the study was applicable to them.

The vignettes were kept deliberately ambiguous in order to gain a wide spectrum of clinical reasoning decisions and ideas from participants. However, participants in the study commented that they felt there was not enough information given and therefore much of the replies focussed on what they would assess, rather than what information they might give. Further exploration of this using focus groups or face-to-face interviews would offer added insight into the knowledge of dementia practitioners.

## 8.6 Conclusion

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Practitioners are receiving and finding information from a variety of sources, which leads to mixed amounts of practise change and knowledge. These variances are evident in the diverse recommendations made, which are not linked to role type or scope of service but rather is dependent on the individual. This has the potential to cause inconsistencies in the services received by PwD and lead to elements of chance in obtaining specific advice or assessments.

To improve services for people with dementia, there is a need to provide uniformity in particularly from within professions, which means service users can approach or be

referred to practitioners with the confidence that they are receiving the same response to their issues.

Lastly, there is a need for PwD to receive information regarding home adaptation sooner following diagnosis. This could be achieved in two ways: Further training and increased emphasis on providing home adaptation information and advice from practitioners in roles such as dementia advisors and specialist nurses, who routinely follow-up individuals following their diagnosis. Alternatively, provide routine access to practitioners such as OTs, who already offer home assessment and expertise, after diagnosis but prior to crisis, as a preventative measure.

## 9 General Discussion

## 9.1 Introduction

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This chapter discusses the findings from the three studies (Chapters 5, 7 and 8) and how these relate to the original aims and objectives of the research (Section 1.2.1) to understand the adoption and barriers to home adaptation for dementia. It then goes on to evaluate these findings in the context of previous research evidence. Finally, this chapter summarises limitations of the studies with regard to areas where future research may be targeted and the implications for this research.

## 9.2 Summary of Research findings

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### 9.2.1 Home adaptation study (Chapter 5)

The first aim of this study were to increase the depth of knowledge around how PwD, and those with whom they live, adapt their living environments in light of a diagnosis of dementia. The second aim was to determine whether evidence regarding improved physical environments was having an impact on their lives. The results showed that people living with dementia are making small changes to their living space following diagnosis, predominantly to address physical limitations. A lack of awareness of how the physical environment can assist or impair PwD, or a desire to maintain the status quo within the home, mean that where difficulties exist that could be mitigated through the use of home adaptation, changes were generally not considered, for example removing patterned carpets and improving lighting.

A further finding was that there is disconnect between published evidence-based recommendations for home adaptation and physical changes actually being made in the home. This disconnect may be part of a more substantial problem: a lack of appropriate, individualised and credible information and support available to PwD and their carers following a diagnosis of dementia.

### 9.2.2 Information sources study (Chapter 7)

This study had three aims. Firstly, to identify from where PwD and their carers currently access dementia-related information. Secondly, to determine how

trustworthy, credible and understandable PwD and their carers consider the available sources of information. Thirdly, to determine how PwD and their carers would like to receive dementia-related information.

The results showed that good quality and trustworthy internet sources are being widely used by people with family members or friends with dementia. Yet, informed and accessible health professionals as sources of information are still preferred and these interactions influence how well-informed carers feel over the whole disease progression.

The main determinants for information source use are *accessibility*, which includes both the ability to gain information as soon as possible and the ease of use. Secondly the ability of the source to address *specific individualised queries* and therefore offer individualised information. A dichotomy exists between which sources are used and which are preferred.

### 9.2.3 Practitioner home adaptation knowledge study (Chapter 8)

The third empirical study of the thesis aimed to investigate the provision of home adaptation information for PwD and their carers by support services and individuals. This was achieved by asking (i) about where individuals who offer support to PwD and their carers access knowledge about home adaptation for dementia, (ii) which services or practitioner roles currently offer advice about modifying the home environment to PwD and their carers and (iii) what the extent of and method of delivery is for home adaptation advice offered?

The results showed that there is a wide variety of information given out from practitioners which covers the full breadth of published evidence for home adaptation for dementia. However, there was no association between job role or service type and the amount of information or environmental assessment offered. The breadth of information offered and assessment appears to depend on the individual practitioner rather than policy. This diversity has the potential to create an element of chance to the provision of potentially helpful information.

## 9.3 Implications

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The findings of the research contained within this thesis have implications for all of those living and working with PwD and their loved ones. There is a firm evidence base for the positive and negative effects of the physical environments for dementia and efforts are made to disseminate this evidence to people living with, or affected by the condition. Yet, the evidence here shows that current efforts are sub-optimal. This means that people living at home following a diagnosis of dementia are not in receipt of information that could assist them to live more independently and reduce the onset of health and social crises.

Previously published research has pointed to a reluctance of individuals to make changes to their homes due to a feeling that changes were not necessary or helpful (Silverstein, Hyde and Ohta, 1993; Corcoran and Gitlin, 2001). However, since the study from Silverstein, Hyde and Ohta, (1993), awareness of dementia had grown significantly and therefore it is possible that attitudes towards coping with a family member with dementia may have changed.

As stated in Chapter one, dementia is a progressive and symptomatically diverse disease and therefore all interventions are dependent on symptoms which are represented in the present. The evidence here appears to show that this is especially true in regard to making changes to the home environment. Individuals only see the need for changes to the home once difficulties become a problem. However, this also limits the number of environmental interventions which are available or practical at the time, due to worsening symptoms or social environment. The evidence indicates two reasons that this may occur:

Firstly, data from the practitioner-based study (Chapter 8) shows that Occupational Therapists provide the most thorough information about changing the home environment to assist with daily living tasks. However, most occupational therapists are only available through a referral from other health practitioners. This means PwD can only access this help once a problem has



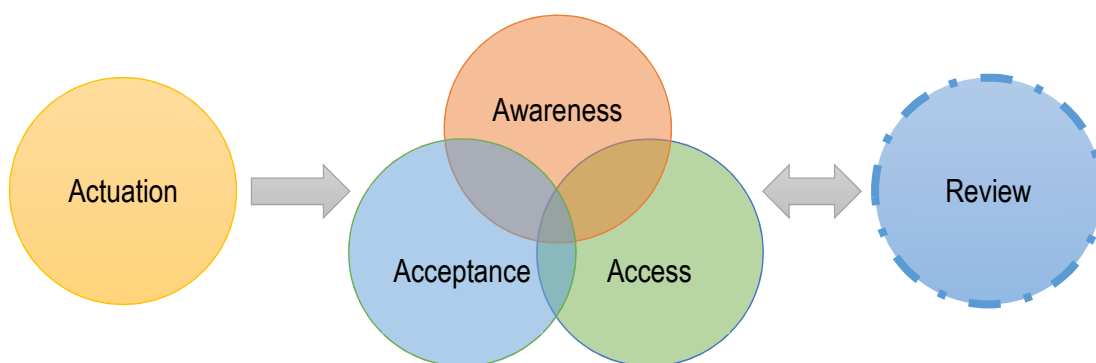
already been identified, and information is limited to that which relates to specific issues which are highlighted through professional assessment.

Secondly, Chapter 7 revealed the dominance of the internet as a source of health information, which means that for those without a previous understanding that their home environment can be altered to assist their dementia symptoms, finding this information is a matter of pure chance. Building an internet search strategy requires cognitive skills and prior knowledge in order to specify search terms and monitor the results lists from search engines (Sharit *et al.*, 2008). PwD and older people in general, often lack these skills and knowledge due to the nature of cognitive impairment and inexperience with the technology.

### 9.3.1 Behaviour change models

If we take the model of health behaviour change described in Chapter 3, this model can now be augmented in light of the research findings. The three interconnecting themes of awareness, acceptance and access were suggested to impact on the implementation of home adaptation in the homes of PwD (Figure 1Figure 8). It was also hypothesised in Chapter 3, that within long term conditions (such as dementia) these three themes need to be preceded by actuation: the need for a trigger which initiates both the potential need change and the receipt of information.

Previous research evidence exhibits a tendency to investigate awareness, acceptance and access as individual attributes but the research findings in this thesis point to a model where actuation, awareness, acceptance and access need to be addressed before changes to the home environment are carried out (Figure 34).



*Figure 34. The Four As of influence in home adaptation implementation*

If we take these themes and place them alongside the Transtheoretical model of health behaviour change (Prochaska and DiClemente, 1982) as discussed in Chapter 3, the findings of the research can be placed within the different stages.

### 9.3.1.1 Actuation

Actuation begins with a diagnosis of dementia. Prior to this, home adaptation specifically for dementia is speculative. Once a diagnosis is received, then individuals enter the pre-contemplation phase with regards to home adaptation for dementia, where individuals are more attune to information about dementia but, they are unaware of how the environment could be changed to assist living with the condition. Following this, two routes can lead towards the use of home adaptation. The first route is directly into the awareness stage where individuals have received knowledge about home adaptation from passive sources. This pathway relies on the level of post diagnosis support and the knowledge of those providing this support.

Lack of support following a diagnosis of dementia was a strong theme in the experiences of participants in the home adaptation study (Chapter 5). This lack of support left both the individuals receiving the diagnosis and their close relatives with whom they live to find their way through a myriad of information without previous knowledge or guidance. Both of these are examples of modifying factors which influence the behaviours individuals take towards living with dementia and how well they cope with day to day challenges created by the condition, including those which can be moderated by home adaptation.

### 9.3.1.2 Awareness

Research has focussed much attention on the acceptance of home adaptation within the homes of PwD. However, evidence suggests that individuals avoid home adaptations because they do not feel that they are necessary (Silverstein and Hyde, 1997; Marquardt *et al.*, 2011). Yet, evidence presented in Chapters 5 and 7 indicate that it is awareness of information that has the greatest influence. In turn, these findings show that the awareness stage of behaviour change is influenced by a number of factors;

- The level of knowledge of charity, health and social care professionals.
- The destination of referrals that are provided for individuals with newly diagnosed dementia.
- The ability of individuals to use the internet effectively.
- The ability of the individuals to absorb and act on the information that is provided.

Data gathered in Chapter 7 shows that for family members and friends of those with dementia, their age and level of education attained affects their ability to seek and understand health information. This was demonstrated by differences in breadth of information searching and the participant's perceived ability to absorb the information offered. This adds support to previous research discussed in Chapter 3 which links demographic factors to health literacy (Baker *et al.*, 2000; Holman, 2015).

### 9.3.1.3 Acceptance

Research has shown that demographic characteristics through their influence on health literacy, affect how likely individuals are to pass through the acceptance phase to contemplation and preparation to make changes. Health literacy and cognition have been shown to influence the use of active information searching (Sharit *et al.*, 2008). Acceptance of the diagnosis and denial also have an effect on acceptance of the need for home adaptations and equipment. This is caused by both the acceptance of what the future may hold with a progressive and ultimately life ending disease and the perceived stigma attached to dementia. This can be seen in both the home adaptation

(Chapter 5) and practitioner (Chapter 8) studies, where adaptations aimed at supporting physical difficulties (seen as part of the general ageing process) were more likely to be recommended and implemented than those to support cognitive impairment. Once again, this supports previous research findings that physical impairment leads to more home adaptations than cognitive impairments (Jutkowitz *et al.*, 2012).

The disparity between the use of home adaptation for physical, cognitive and behavioural symptoms is also a reflection of a lack of dementia specific information and awareness. Participants in the home adaptation study (Chapter 5) had seen others put up grab-rails and stair lifts so they had previous experience and a prior awareness of these adaptations, which feed directly into the awareness phase of health behaviour. As cognitive and behavioural adaptations are used less, they are less visible in the local community, therefore, people living with dementia often do not have personal experience of how to adapt the home in a way which could help cognitive symptoms. This means that there is a greater reliance on passive information to lead them which, as shown in Chapters 7 and 8 incurs elements of chance in the receipt of home adaptation advice.

The design of adaptations also has an effect on the acceptance of home modifications which have been described by health practitioners (Chapter 8) as having negative effects due to the feeling by PwD that they spoil the look of the home. However participants in Chapter 5 did not voice any negative feelings towards the appearance of equipment and living aids. This may be evidence of a disparity between general feelings about equipment and feelings about specific pieces of equipment which are being offered. This could also relate to the amount of items of equipment being fitted, as once the equipment is numerous it potentially has a more significant effect on the aesthetics of the environment.

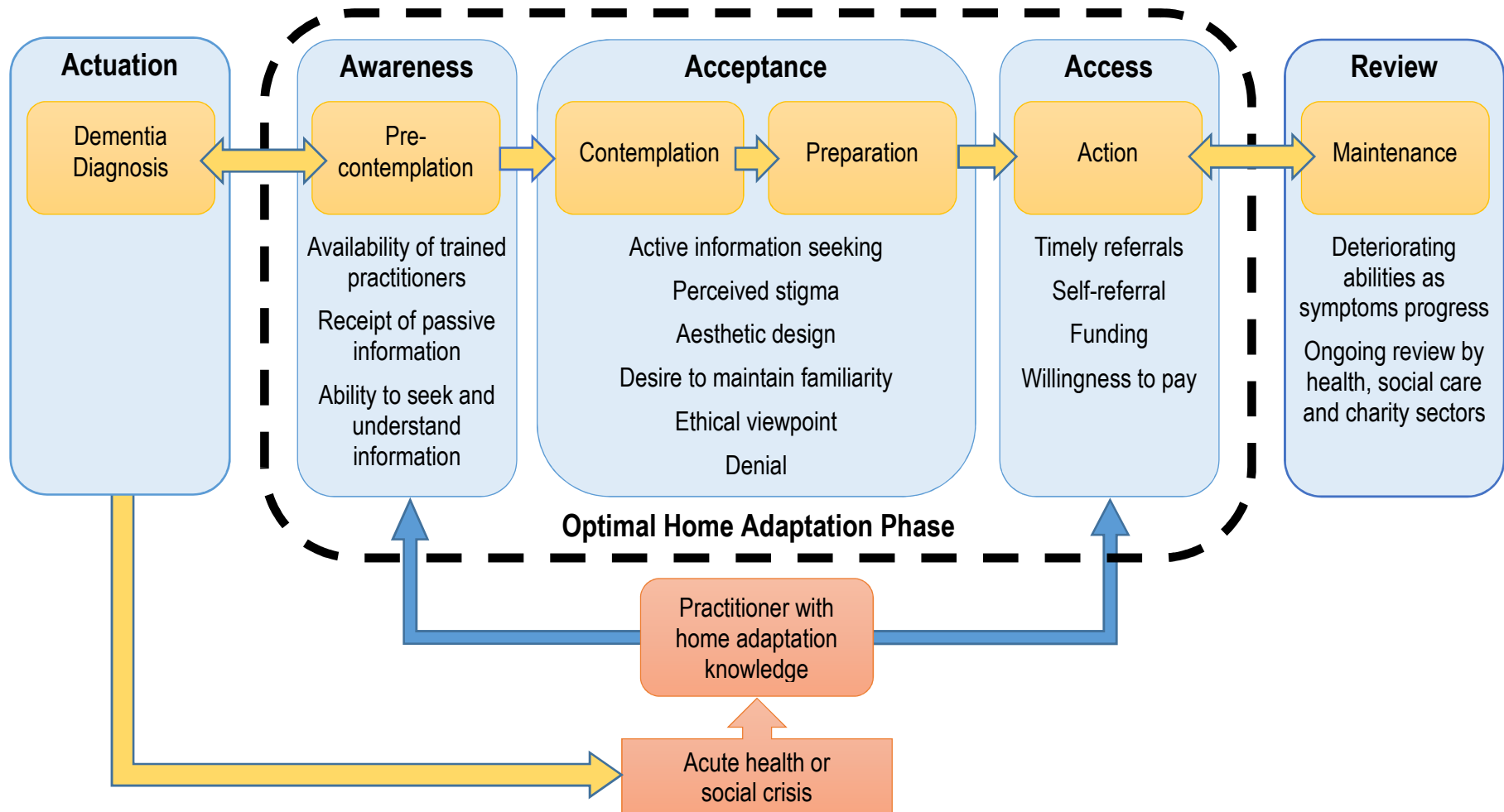


Figure 35 Home adaptation in dementia framework

The Home adaptation study (Chapter 5) also showed that both carers and PwD living at home often did not think about the future and were even informed not to do so by health practitioners in some instances. This represents a denial response which then prevents individuals making practical steps within the home to prepare for future impairments at a time when changes can be made.

The desire to maintain familiarity in the home was a running theme presented in both the home adaptation study (Chapter 5) and the practitioner study (Chapter 8). PwD and their families who had more profound dementia symptoms described a reluctance to change the home environment as it was perceived by them that the person with dementia would find the change too confusing. Practitioners also stated that they would be reluctant to advise on some changes as they would affect the familiarity of the environment to the PwD. Yet, the Home Adaptation study (Chapter 5) showed that people who were newly diagnosed or with milder symptoms were already making significant changes to their homes, and were able to adapt to these. However, the changes that were being made were not home adaptations designed to aid living at home with a long term condition but rather aesthetic or routine decorative alterations. Once again this indicates an urgent need for appropriate home adaptation advice and support at a time nearer to initial diagnosis, if home adaptation rates are to improve.

#### **9.3.1.4 Access**

The study here was conducted in the UK, therefore willingness to pay was a less decisive factor in the choice of adapting the home. It was mentioned only briefly in interviews with PwD (Chapter 5) and not considered a defining factor in the uptake of home adaptation. However, practitioners felt that the adaptations that were least likely to be completed were those addressing colour and décor. These are examples of changes that are not funded through health and social care in the UK, which could mean that cost is influential to this, although further investigation into the causal factors for this is required.

Access to appropriate services or professionals who may be able to assist with issues around the home was a more significant factor than the cost of devices. The

professionals who offer the higher levels of home adaptation, for example OTs, were those predominantly accessed only after a health or care crisis. Therefore, home adaptation is not being used as a tool to prevent health crises.

#### **9.3.1.5 Review**

The research presented in this project has highlighted the need for a fifth theme, the review of adaptations and equipment once they have been completed which fits in the Transtheoretical model of health behaviour change at the maintenance level, where changes are integrated into routine (Prochaska and DiClemente, 1982). As previously described, dementia is a progressive disease and therefore individual need is always changing. Tasks which could previously be completed with ease, progressively become more difficult and these changes to personal ability and caring interactions may mean that previous adaptations require changing to continue to meet individual needs. Therefore, home adaptation which once could be tolerated and adapted to may become difficult to use with the progression of the disease. Additionally, adaptation which once met an individual's need may need supplementing to meet ongoing requirements.

These changing needs reflect those that were explored by Nahemow and Lawton, (1973) in their Ecology of Ageing. Adapting the environment is a dynamic process which aims to create Person-Environmental fit and reduce the effects of environmental docility, therefore a single phase of home adaptation is unlikely to produce an optimal solution for PwD. This is further supported by the study by (Pettersson, Löfqvist and Malmgren Fänge, 2012), who found that home adaptations in general need updating over time. The changing nature of dementia means that ongoing review by knowledgeable practitioners or well-informed family or friends could help to keep an optimal environment over the span of the disease. However, on-going review programs for dementia are inconsistent across geographical areas. The findings of the home adaptation study (Chapter 5), showed that participants felt that on-going health and social care dementia services were poor and left them feeling isolated and without support following diagnosis.

These themes of adapting to changing needs were highlighted within the home adaptation study and through the experiences of practitioners in Chapter 7. OTs who had undertaken home adaptation training, described that the training had led them to consider how home adaptations and equipment could be reviewed and improved. This review by professionals could assist in making these changes optimal to meet the needs of service users; a problem also described by Pettersson et al. (2012).

#### **9.3.1.6 Alternative route**

There is evidence of a second route through the home adaptation behaviour change model suggested in Chapter 3, for those who suffer a health or social care crisis either immediately prior to or soon after a diagnosis of dementia. A crisis creates a more rapid pathway into health and social care services which then respond in order to prevent admission to or support discharge from hospital. These are the practitioners who are able to offer the most comprehensive advice regarding adapting the home environment. Due to the urgency of the situation and pressures on the healthcare system, these practitioners can bypass or increase the transitory rate through the acceptance phase as could be seen in the home adaptation study (Chapter 5), where participants who had a health crisis had the highest level of home adaptation.

### **9.3.2 Optimal Home Adaptation Phase**

Throughout the data gathered in the three empirical studies, the importance of time versus disease progression is evident. Following diagnosis there is a period of coming to terms with the condition, this is followed by a period of living with dementia and a desire to maintain a good quality of life and continue to function in the best possible ways. It is often in this period that PwD then choose to move house, redecorate or make significant changes to their living environments, as discussed in Chapter 5. This is a prime opportunity to make adaptations to the home.

Following this post-diagnosis period, dementia symptoms such as memory loss and reduced mobility can prevent large changes to the domestic environment as both the PwD and those whom they live with rely on the familiarity of home to maintain independent wayfinding. For those who live with PwD, large scale changes such as



fitting new appliances and redecorating also become too time consuming to complete as their time is taken with the increased task of providing care. These issues are reflected in the results of all three studies.

The OHAP is important because it defines a distinct timeframe for PwD within the home adaptation in dementia framework (Figure 35). Within this timeframe, individuals must pass through the awareness, acceptance and access phases of health behaviour change. Therefore the sooner following diagnosis (and entering the OHAP) that people have access to the modifying factors such as passive information and input from trained practitioners the more likely it is that PwD will be able to make and adapt to changes in their homes.

## 9.4 Recommendations for increasing the uptake of home adaptation for dementia

Taking the findings from the presented studies within the thesis and previous research evidence, recommendations can be extracted which would positively influence the uptake of pre-crisis home adaptation within the homes of PwD. These recommendations can be classified into three groups: those for PwD and their carers, those for practitioners and those responsible for service funding and finally recommendations for designers and the retail sector. These recommendations and their chapter derivations can be seen in Table 30.

Target group	Recommendation	Chapter
PwD and their Carers	Proactive home adaptation can provide long term support	2, 5
	Consider how domestic changes and new technology will affect dementia symptoms	5
	Use a broad range of relational and non-relational sources to feel well informed about dementia	7
Practitioners and service leads	Earlier provision of home adaptation information	5, 8
	Benefits of early adaptation	2, 5
	Improved training	7, 8
	Service change to focus on pre-crisis intervention	8
	Providing free of charge, evidence based information	2, 5, 8

	Provision of individualised information	5, 6, 7, 8
Designers and retail sector	Mainstream dementia information and design	2, 7
	Retail opportunities lie within dementia design	2, 5

*Table 30. Summary of recommendations and their derivations*

A findings leaflet based on these recommendations can be found in Appendix I. The leaflet is intended to aid the dissemination of the project findings within the three groups of potential beneficiaries as outlined above.

### **9.4.1 Recommendations for PwD and their carers**

Importantly, there are recommendations that can be made for people living with dementia, these can help to affect the long term quality of life for both the individual with dementia and those close to them.

#### **9.4.1.1 Proactive home adaptation can provide long term support**

Evidence suggests that home adaptation can prevent the onset of crisis (Hwang *et al.*, 2011; Toot *et al.*, 2012), reduce feelings of carer burden, and promote independence for PwD (van Hoof *et al.*, 2013). Whilst adaptations assist in regaining lost abilities following a health or social care crisis, these crises can be avoided or delayed by introducing home adaptation proactively, for example, fitting hand rails, improved task lighting and removing over stimulating décor (Pollock and Fuggle, 2013).

#### **9.4.1.2 Consider how changes and new technology affect dementia symptoms**

When making changes to the home such as redecorating, purchasing new appliances and technology, it is important that families living with dementia realise that these changes can alter how a person with dementia is able to function, both positively and negatively. For example new technology may be unfamiliar and mean that the PwD can no longer use it. (As shown in the home adaptation study, Chapter 5).

#### **9.4.1.3 Use a broad range of sources to feel well informed about dementia**

Using a mix of different information sources, for example asking questions from health professionals, conducting internet searches and speaking to family and friends, helps individuals to feel well informed about dementia. This effectively triangulates information sources and assists in an individual's ability to check the quality of information, whilst providing an increased level of accessibility (Chapter 7).

#### **9.4.1.4 Consider making changes to your home before issues arise.**

There exists an OHAP, which is the best time to make changes to the home. This phase begins as soon as an individual receives a diagnosis of dementia, this means the sooner that individuals feel that they can consider adapting their home, the larger the benefits that these adaptations will provide. Due to the OHAP (as defined in chapter 5) changes to the home environment are less likely to cause confusion and anxiety if made closer to diagnosis.

### **9.4.2 Recommendations for practitioners and service leads**

Practitioners in differing roles are present throughout the disease process, from pre-diagnosis until end-of-life, therefore they are a vital source of information and support for those affected by dementia (Chapter 7). Not only is this important to the individual but the recommendations made here have the potential to positively impact the financial costs relating to service delivery for dementia (Powell *et al.*, 2017).

#### **9.4.2.1 Earlier provision of home adaptation information**

Include information about home adaptation and how this can positively influence living well with dementia in post-diagnosis passive information. This could include (but not limited to), inclusion in booklets, signposting to online information and patient information sheets. Passive information is a positive step towards encouraging active information seeking and acceptance (Chapters 3 and 7). Encouraging this information seeking process earlier increases the chance of home adaptations being carried out within the OHAP thereby making them easier to adapt to (Chapter 5).

The provision of dementia advisors by some healthcare trusts provides a relational source of information for people newly diagnosed with dementia. These advisors, which offer face-to-face contact more regularly than traditional healthcare teams are beginning to improve the provision of early dementia information. However, as shown in chapter 8, these advisors are often lacking in home adaptation knowledge and therefore require further training.

#### **9.4.2.2 Benefits of early adaptation**

Early home adaptation information would also benefit from the subtle inclusion of information which makes it clear that due to the progressive nature of the condition, home adaptation and equipment is better considered early in the disease process when it can be adapted to (As shown in Chapters 5 and 8). The OHAP is important and should be considered by all who offer adaptation advice.

#### **9.4.2.3 Improved training**

Practitioners who work with PwD, particularly those who have contact prior to periods of crisis, for example: dementia advisors who work for dementia charities, and GPs require specific training in how the home environment can help support those with dementia. Providing training for practitioners would help to provide consistent support and information and prevent the element of chance observed in home adaptation advice from practitioners (Chapters 5 and 8).

#### **9.4.2.4 Service change to focus on pre-crisis intervention**

Secondary to the above, improving access to Occupational Therapists following a dementia diagnosis and within the OHAP would assist with the receipt of passive information. Occupational therapists are also able to assess the home and make recommendations. However currently their skills are not accessible until a crisis point has already been reached (Chapters 5 and 8).

#### **9.4.2.5 Providing free of charge, evidence based information**

There is a need for a comprehensive, free information resource regarding home adaptation for dementia. Currently, websites and information sources are very

selective in their provision of evidence based recommendations, books are available at a cost to the individual (Table 4) or information is produced from companies who are selling equipment which makes their advice liable to bias (Chapter 2). All of these limit those who are able to access the advice. The evidence found in the presented studies has shown that internet use is widespread amongst those who care for someone with dementia and a web based repository for the placement of home adaptation information would be accessible as an adjunct to signposting from frontline healthcare professionals (Chapter 7). A single, comprehensive resource would also make it more responsive to new evidence, techniques or equipment which becomes available.

#### **9.4.2.6 Provision of individualised information**

The one-size-fits-all method of information provision is not being effective in dementia. Creating building blocks of information for dementia, including home adaptation means that information can be personalised and given at a pace and a time that reflects both the stage of dementia, their ability to take on health knowledge and the level of acceptance of the condition currently experienced by patients, service users and consumers (Chapters 5,7 and 8).

### **9.4.3 Recommendations for designers and industry**

People working within design and mainstream retailers such as within DIY and home furnishing sectors, have a great influence on how dementia is perceived by those with and without the condition. For the retail sector, enabling people to live well with dementia has potential benefits.

#### **9.4.3.1 Mainstream dementia information and design**

There are current advances being made in the reduction of stigma in dementia, created by increased public awareness and campaigns such as ‘Dementia Friends’ (Department of Health, 2015). As dementia knowledge reaches the public domain, there is an opportunity for mainstream designers and high street retailers to create products and services with dementia in mind. This would create a cyclical process

where improved design itself helps to lower stigma and encourages further design innovation.

Reducing stigma in this way will affect the modifying factors related to health behaviour change (Becker, Drachman and Kirscht, 1974) and assist individuals to move between awareness and acceptance of home adaptations as shown in the Home adaptation in dementia framework (Figure 35). Once again these approaches would enable a greater level of home adaptation to take place within the OHAP.

#### **9.4.3.2 Retail opportunities lie within dementia design**

Dementia is a growing problem, in 2017, 850,000 people have dementia in the UK, and by 2050 this is predicted to be two million (Prince *et al.*, 2014). This is believed to be a conservative estimate due to current under-diagnosis. As dementia diagnosis rates improve and occur earlier in the disease process through improved awareness, there is a growing market for well-designed, practical and aesthetic living aids and equipment which offer an alternative to the utilitarian equipment which is offered through health and social services. This impacted on the ageing of the 'baby boomer' generation (those born between 1946-1964), who are now aged between 50 and 70 and have differing expectations from the generations that came before (Davies, 2015).

#### **9.4.4 Recommendation Priorities**

To implement these recommendations, it is important to consider the process by which they could be implemented and an appropriate order of priority. Recommendations addressing information provision, are of the earliest priority. This is because, as discussed in chapter 7, in order to begin a search for information there needs to be an awareness that there is information to be found. Therefore the recommendations relating to the provision of free of charge, individualised information are those which have the greatest priority.

This is linked to the recommendation for service leads to provide improved training for practitioners and dementia advisors, in order for them to provide good quality early information. The importance of early information is shown in the Home

adaptation for dementia framework (Figure 35), where it is the receipt of information and the availability of suitably trained practitioners are factors which enable individuals to pass from the awareness to the acceptance phases of the framework.

To pass through the acceptance phase the priorities for the recommendations change to those relating to reducing stigma through design and promoting the benefits of making early adaptations. It is also important at this stage that PwD and their carers actively use multiple information sources to become well informed.

These recommendations which improve the ease in which individuals move between phases the framework also increase the likelihood of adaptations being made within the OHAP and therefore, increasing the uptake of home adaptation for dementia in domestic dwellings. There is also a need test these recommendations and priorities to examine where gaps may be present, and to define a structured pathway to implementation.

## 9.5 National and International dementia trends

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As stated in Chapter 1, dementia is a growing problem both in the United Kingdom (UK) and throughout the world. 9.9 million people are diagnosed with dementia every year (World Health Organisation, 2018). This is creating enormous pressure on the healthcare systems of many countries.

Around 1% of the world's gross domestic product is spent on dementia and this is rising (Department of Health, 2013a), of the money spent in the UK on dementia 41% is spent on accommodation costs. This includes hospital and residential care fees. Therefore there is a growing emphasis on creating domestic housing that meets the needs of people with dementia for longer, which ultimately lowers the economic burden on government funding.

To begin to address some of these issues, in 2017 the Dementia Housing Charter was published by the Alzheimer's Society in the UK. This document outlines how housing associations and health and social services should approach the provision of housing

for people with dementia (Moore *et al.*, 2017). Organisations signing up to the charter should “Ensure dementia design principles (and other relevant design) are incorporated, including people living in their own homes.”(Moore *et al.*, 2017 p38). The charter also states that staff within organisations should have appropriate training to be able to advise individuals where to find information about adaptations and dementia and what adaptations may be required.

Improved staff knowledge and better information provision is also a feature of the Prime Minister’s Challenge on dementia 2020. This five year plan launched in 2015 aimed to improve support and information following a diagnosis of dementia (Department of Health, 2015). What the results here show, is that in some areas such as home adaptation, there is still much improvement to be made.

Also in 2017 the first draft of the World Health Organisation’s ‘Global Plan for Dementia’ was launched. The plan, which has since been updated, outlines what the key focus of governments should be in relation to dementia. One of the key themes of the plan is for individual countries to develop strategic plans for dementia, which involve different sectors such as health, social care, housing, education and industry. This collaboration should be used to create a wide-reaching shift in the provision of dementia services (World Health Organisation, 2017, 2018).

What the Dementia friendly housing charter and the Global plan for dementia both recognise is the importance of multiple agency involvement in dementia. The size and breadth of issues caused by dementia for individuals, families, communities and nations is no longer seen as the proviso of just health and social care. In order to improve quality of life and reduce reliance on services it is vital to find ways to enable PwD to live successfully for longer without crisis. The recommendations within this work, show that in the field of home adaptation for dementia, cross- sector information provision and development is also important. It is through the involvement of industry, health and social care and PwD and their carers themselves that the living environments of PwD can be improved at the most appropriate time.



There have been some advances made in the provision of novel ways to access home adaptation information for those living in domestic dwellings. The Dementia Services Development Centre have recently launched a smartphone app called Iridis, which aims to provide increased individualised home adaptation advice using camera images to produce information relating to specific rooms (Palmer, 2018). Although this represents a step towards using new technology to provide more personalised information, it remains unclear what the level of uptake will be amongst the over 65s, who are less likely to use technology like this regularly, as shown in Chapter 6.

## 9.6 Limitations

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Whilst stringent efforts were made to remove bias and inconsistency from each of the research methodologies it is important to acknowledge that there were certain limitations.

### 9.6.1 Recruitment

Conducting research using people affected by long term conditions inherently carries challenges with research recruitment, which needs to be completed with tact and understanding. The research here was concerned with people living with dementia (and their close family and friends) who had not yet reached a point of crisis. This meant that the number of services they used, from which they could be recruited, were limited. These issues all impacted on the range and length of time required to recruit potential participants.

For the first home adaptation study (Chapter 5), due to time and budget restraints, sampling was limited to people from the West Midlands region of the United Kingdom. For the second study (Chapter 7), efforts were made to recruit participants from a wide range of places and postal or telephone questionnaires were offered, but no participant requested a telephone call and only 14 replies were received via post. All other replies were received via the online platform. This naturally creates bias of respondents who can use the internet as a resource.

### 9.6.2 Using PwD in research

Conducting research involving PwD as participants is recognised as being vital to the provision of appropriate products and services for people with the condition. However, recruiting PwD as research participants means dealing with challenges. Methodological considerations for this are discussed in Chapter 5. Historically there have been concerns about using PwD in research due to issues relating to consent and concerns regarding the validity of the data they give. Although there is a growing movement towards documenting the feelings and experiences of PwD, problems remain in the obtaining of ethical approval for studies involving PwD. Within this research, to be able to include PwD in the participant dyads for the first study, only those with mild to moderate symptoms could be recruited. This could have impacted on the results from the first study because dementia is progressive in nature and strategies such as home adaptation may become more prevalent during more advanced stages of the disease.

Issues with the ethics of involving PwD in research studies was also apparent in the information sources study. Questionnaires were completed remotely, therefore, it was not possible to assess the capacity and ability of an individual with dementia to participate effectively. This meant that in order to obtain ethical approval for the study, participants with dementia were only able to be recruited if they completed the questionnaire with a family member or friend. This meant that the experiences of PwD were lost in this study at the recruitment stage as only two PwD participated with their family or friends and it was unclear what their input to the survey questions was.

Whilst the information sources survey asked participants about the length of time since dementia diagnosis of their friend or family member, the severity of their dementia symptoms was not addressed. There is a possibility that the sources of information used correlates to the severity of dementia symptoms faced as this may also impact on the amount of time available to carers to spend seeking information and the breadth of information required. Also related to issues of informed consent by participants with dementia, for the first study, participant dyads were given the option to be interviewed together. Combined interviews may have led participants to

withhold experiences or views that the other participant may find distressing and therefore not providing a comprehensive review of their personal experiences.

### **9.6.3 Sample Size**

The third study (Chapter 8) was likely to be affected by the small sample size and the skewing of the participant population towards Occupational Therapists. Despite efforts to recruit participants through a variety of professional and charity groups, uptake remained low. Although suitable numbers of people accessed the first page of the survey, the majority of individuals did not then go on to fill out the survey. This could be for several reasons; perhaps the participant information leaflet was seen as too lengthy and therefore busy practitioners did not feel that they had time to read all of the information offered, or perhaps practitioners who were not dementia specialists did not think the study was applicable to them.

### **9.6.4 Structure of Surveys**

The vignettes used within the practitioner survey (Chapter 8) were kept ambiguous to elicit a wide spectrum of clinical reasoning decisions and ideas from participants. However, replies from participants commented that due to this ambiguity many of the replies focussed on what they would assess, rather than what information they might give.

## **9.7 Future Research**

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Home adaptation research would be considerably improved by exploring further the interplay between internal (for example past experiences and beliefs), and external stimuli (for example the environment, input from professionals) in the decisions made by PwD and those close to them. By understanding more closely the relationship between these factors it will become possible to provide improved personalised information and care and also counteract challenges which are currently preventing PwD in creating environmental adaptations for their homes.

We need to be able to ensure that the right information is available from accessible and trusted sources at the right time. This time appears to be a window characterised by the time between acceptance of the dementia, following diagnosis, and the point where the degradation of symptoms make familiarity in the home a fixed point. How is this OHAP identified, and what can we discover about the underlying processes that lead to a practitioner or person with dementia deciding against change?

It is clear that online sources are becoming increasingly important in the provision of dementia information. However, as reported here, PwD and their close family and friends prefer information from trusted and knowledgeable practitioners. Yet, the level of knowledge regarding home adaptation amongst practitioners is varied and role or service type does not guarantee this. One solution would be to design accessible home adaptation education and resources for practitioners. This would have the benefit of adding consistency to the information provided and onwards referrals made by health and social care professionals. Collaborative design research using a cross-section of dementia practitioners and designers could be utilised to create usable pragmatic resources. Research is needed to explore how new technology can deliver education in the most efficient and effective way.

Although PwD want to receive information from face-to-face contact with knowledgeable professionals, this is the most financially costly way of providing information. This means that these resources are always limited, and therefore health and social care services have systems which involve a referral process (with defined criteria) and appointments need to be made to access them. Unfortunately, for individuals who have queries or problems with their condition, this means waiting for information or answers. With these restrictions in mind, further qualitative research is required to gain understanding of what the core traits are which draw individuals to the information from professionals. Once this is more fully understood these traits or expectations can be developed into innovative technology solutions which take on the desirable traits of both health professionals and online resources. This could involve virtual contact through video conferencing, virtual reality or real-time non visual contact via telephone or messaging. Follow-up research and prototype trials would

then address how effective these new technologies are and how PwD adapt to new types of contact.

The Transtheoretical Model of Health behaviour change and health belief model shows that internal factors play an important role in the uptake of new health behaviours (Becker, Drachman and Kirscht, 1974; Prochaska and DiClemente, 1982). These factors include health literacy, previous experiences, education and demographic information. Other factors that affect uptake of information are the acceptance of diagnosis and stage of the condition. These factors, whilst all important, are individual in nature. If practitioners or suppliers of information were able to quickly and reliably assess information needs, including all of the factors shown above, then information could be individually tailored and thus improve both person centred care and the usefulness of information to the individual.

Technology could possibly supply the answer to this with a simple questionnaire and appropriate algorithm which matches responses and provides information at both an appropriate level and depth. This work would require the collaboration between applied engineering and health and social care. Specialisms including human factors, design, psychology and visualisation could collaborate in order to create an accurate and appropriate assessment coupled with a novel method of delivery.

Suitable identification of learning and information needs could also allow health professionals to build information building blocks which could then be combined to find bespoke responses and make the time spent in face-to-face appointments more efficient and useful. New assessments and measures first require a thorough systematic review of current health literacy and dementia acceptance measures, followed by the extrapolation and creation of the new measures and user trials in order to validate the new measures.

Once the new measures are validated, focus groups and collaborative design workshops involving practitioners and service users would be used to define the design requirements of the new technology, followed by the creation of prototypes and user studies.

Other concepts which need to be considered are the opportunities which a more global approach to awareness may create. Given the ageing population and the high rates of dementia, creating more mainstream provision of information regarding how home adaptation for dementia could be included in domestic design features may be a beneficial step. For example providing home adaptation for dementia information at the point of sale in mainstream retail premises e.g. DIY stores. This has the possibility to reach those who have perhaps not yet come to terms with a diagnosis of dementia but are looking to make cosmetic changes to their home.

By improving the engagement of the retail sector and treating people living with dementia and their family and friends as consumers of equipment rather than patients or service users, there is an opportunity to remove some of the stigma attached to making changes to the home in light of poor health. Incorporating merchandising, retail strategies and using known consumer behaviour techniques within the living aid and home adaptation sector could break down some of these obstacles. This is particularly important in order to encourage PwD and their carers to make changes prior to reaching a crisis point.

Future research would be considerably improved by more meaningful input from PwD. National and international policy advances mean that diagnosis rates of dementia are improving and more people than ever are receiving treatment for dementia. This means that more individuals are living well with the disease and are able to function independently or with little assistance. This means that PwD remain in employment, drive and have meaningful input into society. Academic research policy must keep pace with this and find ways of encouraging participation from PwD. More research is needed to discover the reliability of data when received from those with dementia and at what level they can engage without formal assessment of their capacity, which for many is seen as derogatory and insulting, which then reduces the scope of research methodologies available to answer complex research questions.

## 10 Conclusions

## 10.1 Conclusions

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The overarching aim of the research was to discover how people living at home with dementia were using adaptations to assist them in their lives, what the barriers to using home adaptation in dementia are and how an increased uptake of home adaptation can be achieved. The conclusions presented are according to the original Research Objectives (Chapter 1).

### 10.1.1 Research Objective One: To discover the lived experiences and perception of home adaptation by PwD and their carers

Evidence from the limited body of existing research discussed in Chapter 2 indicates that people with dementia and their carers are reluctant to adapt their homes as they feel that these changes are not needed. When seen through the prism of health behaviour change models, this shows that home adaptation is rejected at the contemplation and acceptance stage, where perceived threat e.g. risk of falling, was the defining factor in the choice of whether or not to adapt the home.

The first study in this thesis highlighted a lack of awareness of how the home environment can be adapted to aid dementia symptoms, which is potentially preventing PwD and their carers being able to effectively consider home adaptation as a concept which could assist them. This indicates that barriers to acceptance of home adaptation do not take place within the contemplation stage, but rather the earlier stage of awareness (pre-contemplation) is more influential to home adaptation implementation.

Furthermore, PwD and their loved ones describe feeling lost and left to find their way following their diagnosis due to a general lack of information and support. This represents a breakdown in the information pathway which may cause the advice regarding evidence-based home adaptation for dementia to not reach those who would benefit from its use.



Additionally, following a dementia diagnosis, a window of opportunity exists when symptoms are at a more mild stage. During this stage changes to the home can be made and adjusted to. The end of this window is the point where an individual's dementia symptoms have progressed to a point where changes to the physical environment can't be tolerated because of the need to maintain familiarity in order to maintain their level of function. This OHAP is a key point to consider for those designing home adaptation services and information services. If the information and services are offered too late e.g. when a health crisis has occurred there is a greater chance of them being rejected.

### **10.1.2 Research Objective Two: To investigate the information seeking preferences and behaviours of PwD and their carers**

Information seeking behaviour amongst people with a close family member or friend with dementia is influenced by a number of factors. The most defining demographic was age group, with older people less likely to rely on online sources to seek information about dementia. However, this was not due to a lack of access to the internet, rather it is linked to habitual processes. Whilst internet sources are widely used, they are not preferred. Health professionals remain the favoured source of dementia information. However, the results from the empirical studies in this thesis do indicate that health professionals need to have specialist dementia knowledge and be more accessible to people with dementia to meet the expectations placed upon them.

In order to meet the needs and desires of people with dementia and their carers an effective information pathway needs to be created. The results contained herein suggest that information sources need to provide individualised information, answer specific questions and be accessible. This means that information sources need to behave like a conversation with a health care professional, but in a way which is as accessible as using online sources.

### **10.1.3 Research Objective three: To investigate practitioner knowledge and practise in relation to home adaptation advice**

The results suggest that whilst most practitioners working with PwD demonstrate awareness about home adaptation in dementia, there is great variation in the level of knowledge and the approach taken to assessment and onward referral. These differences exist between practitioners within similar roles and services and there is little homogeneity in home adaptation knowledge by practitioners.

In addition, it was found that Occupational Therapists offer more depth to their advice and assessments and are the most common profession to whom people with dementia will be referred to for environmental issues. However, Occupational Therapy services are predominantly designed for the management of health or social care crisis and therefore, not accessible proactively for crisis prevention.

In order to meet the needs of people seeking dementia information and advice about difficulties they may be experiencing, there needs to be consistency within service provision. This could be created through improved practitioner education regarding how the physical environment can be changed to mitigate dementia symptoms and support independent living or by improved referral or self-referral routes into Occupational Therapy services earlier in the disease process.

Improved provision of education and home environment assessment by specifically trained practitioners would enable individuals to pass through the stages of the home adaptation in dementia framework (Figure 35) more quickly and therefore enable home adaptations to be made whilst within the OHAP (Figure 13).

These findings were then combined to create recommendations aimed at influencing the uptake of home adaptation for dementia in domestic dwellings. These recommendations are aimed at PwD and their carers, practitioners and service leads and designers and industry. The research findings, coupled with the corresponding recommendations, create exciting opportunities for further research and development. This includes the use of technology to improve information provision

via accessible, individualised methods and the influence of targeted information on the uptake of home adaptation for dementia.

#### **10.1.4 Final Remarks**

Dementia is a worldwide problem, and prevalence is growing. By 2050, it is estimated that 131.5 million people will have the disease and health and social care systems are already struggling to provide services for dementia (Prince *et al.*, 2014). Supporting people living with dementia to remain independent and free from health crises has the potential to help relieve some of the financial and logistical burden of the disease. Not only that, but older people want to remain living in their own homes for as long as possible where they live in familiar environments and communities. Therefore, achieving improved rates of home adaptation through better information provision, practitioner training and services is an invaluable opportunity to be able to assist PwD, their loved ones and health and social care systems together.

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## 12 Appendices

## 12.1 Appendix A: PIL Home Adaptation Study

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### PARTICIPANT INFORMATION LEAFLET

**Study Title:** The use of Home Adaptation by people with dementia

**Investigator(s):** Frances Allen

#### Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### PART 1

##### What is the study about?

This study forms part of a PhD research study within the WMG at the University of Warwick. It seeks to understand more about how and why people living with dementia adapt or change their homes to cope with the demands of the disease.

##### Do I have to take part?

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

##### What will happen to me if I take part?

The investigator will contact you via the telephone number you have provided to arrange a convenient time to come to your home and conduct a brief interview (approx. 30 min – 1 hour) about you and your home.

On the day of the interview:

1. The researcher will come to your home at the prearranged time and speak with both you and the other participant who lives in your home.
2. The researcher will then show you this participant information leaflet again where you will have the chance to ask any questions.
3. If you are happy with the information, the researcher will then ask you to sign a consent form.



4. The interview will then begin.
5. The interview will contain questions regarding how your home has changed since receiving a diagnosis of dementia, how this had made you feel about your home and where you have received home adaptation advice or information. Some of the interview questions will be for participants with dementia and some for others living in the same home.
6. If there are any aspects or adaptations of your home that are hard to describe or particularly relevant, then photographs of these specific areas may be taken with your permission.

Interviews will be audio recorded and the researcher will take notes regarding the content of items discussed.

#### **What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?**

It is not foreseen that this study will cause any disadvantages to the participants. The interview will require you to think about your home and actions you have taken, if at any time, any of the interview questions make you feel uncomfortable, you do not have to answer them.

If at any time during the interview you become uncomfortable or anxious you will be offered time to take a break before continuing.

#### **What are the possible benefits of taking part in this study?**

There will be no individual benefit to you for participating in this study. However it is hoped that the information gained will help to provide better information and services for people with dementia wishing to remain living at home.

#### **Expenses and payments**

There is no financial reward offered for participating in this study.

#### **What will happen when the study ends?**

Following your interview the audio recording will be transcribed (written word for word) and you will be offered the chance to read back your words and check that they reflect your experiences.

The collected data will be stored on a password protected computer for analysis

#### **Will my taking part be kept confidential?**

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

#### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

**This concludes Part 1.**

**If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.**

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## **PART 2**

### **Who is organising and funding the study?**

This study is funded by the WMG at the University of Warwick

### **What will happen if I don't want to carry on being part of the study?**

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

### **What if there is a problem?**

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact the Chief Investigator of the study details overleaf.

### **Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

#### **Director of Delivery Assurance**

Registrar's Office

University House

University of Warwick

Coventry

CV4 8UW

[Complaints@Warwick.ac.uk](mailto:Complaints@Warwick.ac.uk)

024 7657 4774

### **Will my taking part be kept confidential?**

Yes, written information will not contain your name or any identifiable information. Your name, address and phone number will be used by the researcher only for the purposes of arranging a face-to-face interview and will not be passed to any third parties.

Any photographs taken will not contain images of people or identifying material. Your name will not be used in written transcripts or in any in written or spoken communication.

Collected data will be kept in a locked filing cabinet, at the International Digital Laboratory at the University of Warwick. Data will be stored on a password protected University computer. All data will be stored for 10 years as per the University of Warwick guidelines. Data storage and handling is in accordance with both the Data Protection Act, and the University of Warwick policy.

#### **What will happen to the results of the study?**

The results from this study will be written up and make up part of my PhD thesis. The anonymised data may be discussed with academic supervisors and colleges within the WMG

The completed study may also form the basis of research papers submitted to academic conferences and journals.

#### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee: **15/YH/0352**

#### **What if I want more information about the study?**

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information leaflet, please contact:

##### **Chief Investigator**

Frances Allen  
International Digital Laboratory  
University Of Warwick  
Coventry  
CV4 7AL  
Email: [f.allen@warwick.ac.uk](mailto:f.allen@warwick.ac.uk)  
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Tel: 02476 575951

**Thank you for taking the time to read this participant information leaflet.**

## 12.2 Appendix B: Consent form Home Adaptation Study



### CONSENT FORM

**Study Number:** 15/YH/0352

**Participant Identification Number for this study:**

**Title of Project:** The use of Home Adaptation by people with dementia

**Name of Researcher(s):** Frances Allen

**Academic Supervisors:** Dr Rebecca Cain

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 21/09/15 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical, social care, education, or legal rights being affected. ☐
3. I understand that relevant sections of data collected during the study, may be looked at by individuals from The University of Warwick, from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these records. ☐
4. I understand that some of the answers that I give may be used anonymously as quotes. ☐
5. I give permission for the interview to be audio recorded. ☐
6. I give permission for photographs of areas of my home to be taken where necessary as part of the study. ☐
7. I agree to take part in the above study. ☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

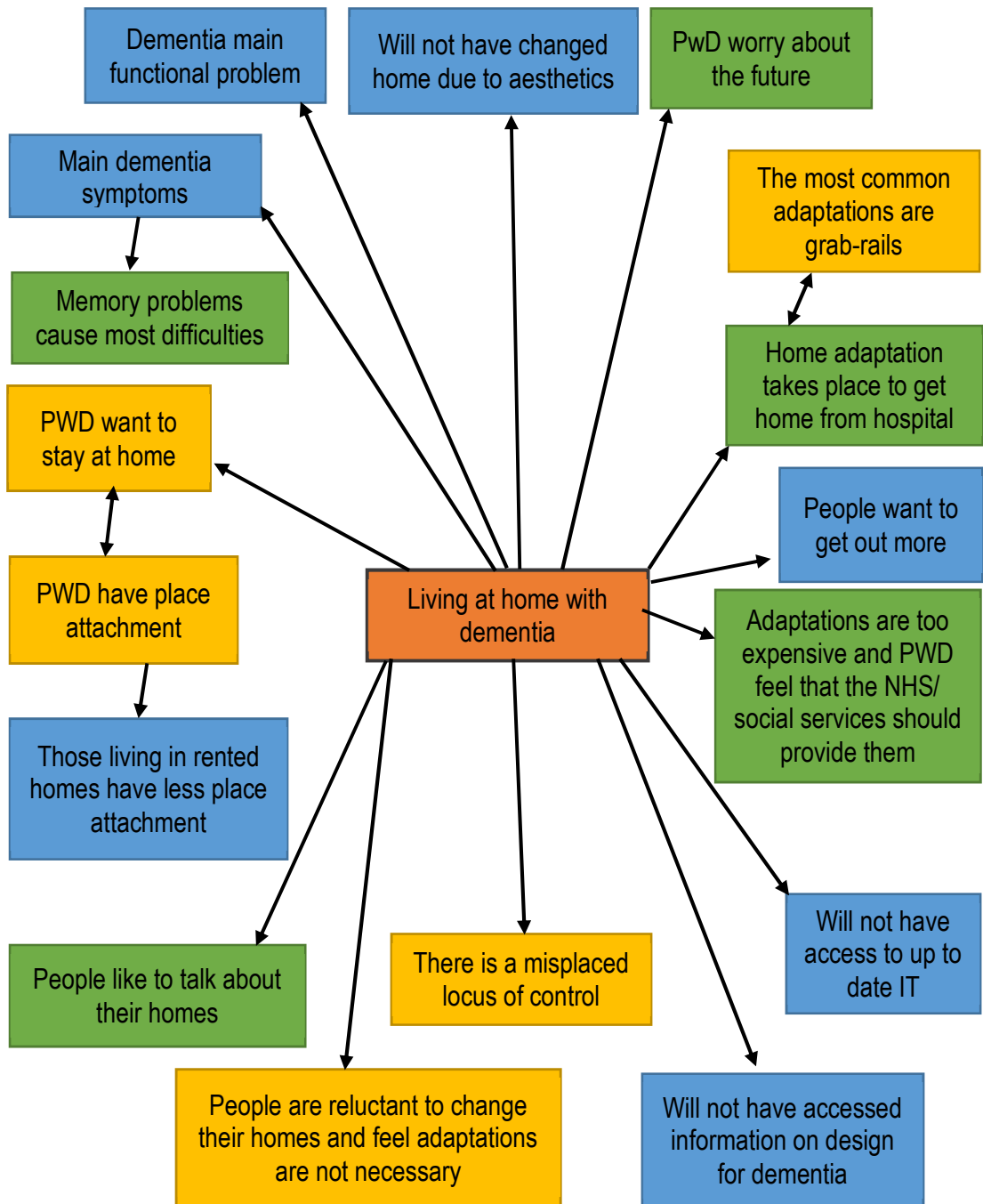
\_\_\_\_\_  
Name of Person

\_\_\_\_\_  
Date

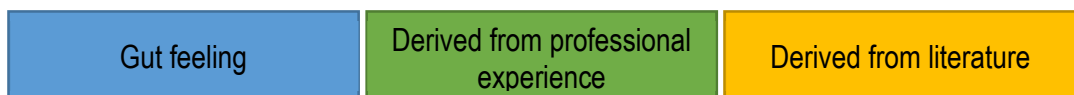
\_\_\_\_\_  
Signature

taking consent

## 12.3 Appendix C: Bracketing framework for Home adaptation study



**Key:**



## 12.4 Appendix D: Interview schedule for Home Adaptation Study

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### Interview Schedule

#### Introduction

My name is Fran Allen and I am a PhD student from WMG at University of Warwick.

Thank you for agreeing to participate in this study. I first of all want to assure you that you will remain completely anonymous for the purposes of the project and no records will be kept with your name on them. The purpose of this study is to gain further knowledge of how and why people and their carers living with dementia adapt their homes.

We are now going to start the interview which should last between thirty minutes and an hour. As described in the participation leaflet, I would like to once again ask permission to record this interview in order that I can have a complete record of your opinions and responses to allow an accurate analysis of the study to be completed.

I first of all would like to talk to .....X.....about your home and then have some further questions for .....Y..... If you would prefer to be interviewed together then that is fine, but it would be of great benefit if I could speak to you both individually initially. Then I just have a question for both of you together. If at any time you would like anything repeated or clarified please ask and you are free to terminate the interview at any time should you so wish.

#### Question areas for participants with dementia

<b>Baseline information</b>	Age? How long ago were you diagnosed with dementia? What would you say are your main symptoms? What do you find most difficult?
<b>Feelings of Home</b>	How long have you lived at this property? What made you decide to live here? What is your favourite thing about living here? What do you like least about living here? How have your feelings about home changed since your diagnosis? What do you think about your future here in your home? Have you considered moving? How important is it that you can continue living in your home?

<b>Access</b>	How often do you get out of the house? Would you like to be able to get out more often? What do you think would help you get out more?
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#### Question areas for Carer / family member

<b>Baseline information</b>	Age? Do you own or rent your home? How would you describe your caring role? Does anyone else assist with care in the home? Do you have any health problems that affect how you move around?	
<b>Home adaptation</b>	Thinking about the time since diagnosis, have you made any changes to the house?	
	<b>Prompts:</b> <ul style="list-style-type: none"> <li>• Added anything</li> <li>• Removed anything</li> <li>• Moved anything</li> <li>• Changed routine</li> </ul>	<ul style="list-style-type: none"> <li>• Bedrooms</li> <li>• Lounge</li> <li>• Kitchen Bathroom</li> <li>• Entrance / hallway</li> <li>• Outside</li> </ul>
	How long ago did you do these? How has this helped / not helped? Why did you make these changes? Did you get any advice prior to making changes? Where did you look for information? How did these changes occur? Is there anything that you are planning to change in the future? What would help you adapt your home further?	
<b>Professional advice</b>	Have you had an assessment of your home and advice from any professionals? In what ways was this helpful or not? Was there anything that was suggested that you did not do? Why was this?	
<b>Feelings of Home</b>	How have your feelings about the house changed? What do you think about your future here in your home? Have you ever considered moving? Why?	

#### Questions for both participants

	What advice you would give to someone wanting to stay in their own home following a diagnosis of dementia?
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## **Conclusion**

I think that has covered all of the things that I wanted to ask. Is there anything that you would like to add or areas that you feel we have missed?

Would you like to see a transcript of the interview once it has been typed?

If you would like to have a full copy of the report once it is finished please let me know.

Thank you once again for your time and patience in participating in this research.

### **If participants are showing signs of agitation or discomfort during the interview.**

Thank you for your help so far, it is really interesting talking to you. Would this be a good time for a break? I will turn off the recording and we can have a rest for ten minutes before continuing onto a different topic if that is ok?

### **If participants are still distressed following the break:**

I can see that you find this upsetting, would you like to continue or we can conclude the interview now. Thank you for allowing me into your home today, it has been really helpful. With your consent I would like to use the information that you have provided up to this point, or if you prefer you can withdraw from the study. If you feel that you would like to speak to someone about the interview there are contact details for the University and myself on the information leaflet.

If you feel that you would benefit from further adaptations to your home or would like an assessment, contact your GP or social services, outline the problems that you are having and they can refer you for an Occupational Therapy assessment.



## 12.5 Appendix E: Information Sources questionnaire derivations

No.	Survey question	Source	Question type	Sample	RQ1	RQ2	RQ3
<b>Section 1 Consent and Screening</b>							
1.	Consent	N/A	Screening				
2.	Do you have a diagnosis of dementia or are you a carer for a relative or friend with dementia?	N/A	Screening				
<b>Section 2 Demographic Information</b>							
3.	How long ago did your family member/friend receive a diagnosis of dementia?	N/A	MC SA	✓			
3b.	How would you describe your relationship with your relative / friend with dementia?		Open	✓			
3c.	Would you describe yourself as? (ethnicity)	ONS	MC SA	✓			
3d.	Would you describe your relative or friend with dementia as? (ethnicity)	ONS	MC SA	✓			
3e.	Gender of respondent	ONS	MC SA	✓			
3f.	Gender of relative or friend with dementia	ONS	MC SA	✓			
4.	What type of dementia has your relative/friend been diagnosed with?		MC SA	✓			
5.	Age of respondent and friend/family member with dementia	N/A	Open	✓			
6.a	Which of the following best describes the highest level of education you have completed?		MC SA	✓			
6.b.	Which of the following best describes the highest level of education your relative or friend with dementia has completed?		MC SA	✓			
7.	Country of residence	ONS	MC SA	✓			
<b>Section 3 Questionnaire</b>							
8.	From which of the following people have you been offered <b>passive</b> information regarding dementia and how would you rate the information that they provide?	Literature	Likert		✓	✓	

No.	Survey question	Source	Question type	Sample	RQ1	RQ2	RQ3
9.	Please indicate if you have ever noticed this type of information from any of the following	Literature	MC MA		✓		
10.a.	Have you ever acted on the information that you have seen either by seeking further information or changing something?	Literature	MC		✓		
10.a.i	Please explain how		Open Qual		✓		
11.	Have you actively searched for information about dementia?	Literature	Y/N		✓		
11.a.	From which of the following places have you looked or asked for information about dementia?	Literature	MC MA		✓		
11.b.	Based on your experiences of seeking information about dementia, how much do you agree or disagree with the following statements?	HINTS survey	Likert			✓	
12.	Please indicate how much you agree/disagree with the following statements	HINTS survey	Likert		✓	✓	
13.	Do you attend or have you ever attended a support group for carers or people living with dementia?	Previous Research	Y/N		✓		
13.a.	Which groups did/do you attend?	Previous Research	Open		✓		
13.b.	Would you consider attending a group in the future?	Previous Research	Y/N		✓		
13.b.i.	Why not?	Previous Research	Open Qual		✓	✓	
14.	Do you own or have access to any of the following?	HINTS survey	MC MA		✓		
15.	Do you go online: emails	HINTS survey	Y/N		✓		
16.	Do you go online: WWW	HINTS survey	Y/N		✓		
16.a	Internet where?	HINTS survey	MC MA		✓		
16.a.ii	Internet how often?	HINTS survey	MC SA		✓		
16.a.iii	If you have looked on the internet for information, which of the following types of website have you used when looking for dementia information?	Literature	MC MA		✓		

No.	Survey question	Source	Question type	Sample	RQ1	RQ2	RQ3
16.a.iv	If you want to find out about an aspect of living with dementia, how likely are you to look for advice on the internet?	Previous research	Likert		✓		
16.a.v	Why?	Previous research	Open		✓		
17.	If you do not go online to access the Internet or World Wide Web please tell us why?	HINTS survey	MC MA		✓		
18.	In general how much do you <b>trust</b> information about dementia from the following sources?	Literature	Likert			✓	
19.	In general how <b>understandable</b> do you find the information provided by the following information sources?	Literature	Likert			✓	
20.	In general how easy to <b>access</b> do you find the following sources of information?	Literature	Likert			✓	
<b>Where would you first seek information on the following and what other sources would you use?</b>							
21.a	Medication?	Literature	MC MA/SA		✓		
21.b.	Memory loss?	Literature	MC MA/SA		✓		
21.c.	Symptom?	Literature	MC MA/SA		✓		
21.d.	Equipment and living aids?	Literature	MC MA/SA		✓		
21.e.	Emotional support?	Literature	MC MA/SA		✓		
21.f.	Practical advice?	Literature	MC MA/SA		✓		
22.	Overall, how confident are you that you can access appropriate dementia information when you need it?	Previous Research	Likert		✓		
23.	In an ideal world, how would you like to receive information about dementia?	Previous Research	Open				✓
23.a.	From your experiences, how close to the ideal do you feel the current sources of information are?	Previous Research	Likert				✓
23.a.i	Why is this?	Previous Research	Open			✓	✓

No.	Survey question	Source	Question type	Sample	RQ1	RQ2	RQ3
24.	Which of these factors do you regard as the most important when considering a source of advice about living with dementia, and which is the least important?	Literature	MC SA				✓
25.	Finally, is there anything else about sources of dementia information that you would like us to know?	N/A	Open	✓	✓	✓	✓
<p>Key</p> <p>MC SA = Multiple Choice Single Answer</p> <p>MC MA = Multiple Choice Multiple Answer</p> <p>Y/N = Yes, No, Not sure</p> <p>Previous Research= Derived from evidence from 'The use of home adaptation advice by people living with dementia and their carers' (Chapter 5)</p> <p>HINTS Survey = Question take from the U.S. Health Information National Trends Survey</p> <p>Literature = Question derived from previous published research</p>							

## 12.6 Appendix F: Information sources postal questionnaire including PIL and consent form

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### **The Information Delivery Preferences of people living with dementia and their carers (InDeP). (Postal version)**

We would like to invite you to participate in the above research study. We are conducting research into the preferences of people with dementia and their carers in accessing and receiving information about dementia. Please find attached a Participant Information Leaflet which details what this research involves, please read the leaflet and if there is anything which you do not understand or would like clarifying please contact the researcher using the details provided.

If you would prefer to complete the questionnaire via a phone-call please contact me and this can be arranged.

Thank you for your time and interest.

Kind Regards

Fran Allen

WMG, University of Warwick.

## **PARTICIPANT INFORMATION LEAFLET**

### **Study Title:**

The Information Delivery Preferences of people living with dementia and their carers (InDeP).

**Investigator(s):**            **Frances Allen**

### **Introduction**

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part.

### **PART 1**

#### **What is the study about?**

This study forms part of a PhD research study within the WMG at the University of Warwick. It seeks to understand more about where people living with dementia and their carers access advice and what they feel about different information sources.

**Do I have to take part?**

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

**What will happen to me if I take part?**

If you decide to take part you are asked to complete a questionnaire which includes a variety of questions about your experiences using different sources of dementia information and what your preferences are. The questionnaire will take approximately 15-20 minutes to complete. Once you have completed the questionnaire, we ask you to return the questionnaire to us in the enclosed pre-paid envelope.

The beginning of the questionnaire asks information about yourself for example your age and gender. The second section of the questionnaire will ask questions about information sources, some will require a simple yes or no answer, others require you to rank given items and others are open ended for your own words.

If you have difficulties reading the questionnaire but would still like to participate, you can contact the researcher via the contact details in Part 2 who will be happy to help you complete the questionnaire via telephone.

**What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?**

It is not foreseen that this study will cause any disadvantages to the participants. The questionnaire will require you to think about where you find information, if at any time, any of the questions make you feel uncomfortable, you do not have to answer them.

**What are the possible benefits of taking part in this study?**

There will be no individual benefit to you for participating in this study. However it is hoped that the information gained will help to provide improved information delivery for people with dementia.

### **Expenses and payments**

There is no financial reward offered for participating in this study.

### **What will happen when the study ends?**

The collected data will be stored on a password protected computer for analysis. Paper copies of returned questionnaires will be anonymous and not identifiable in any way.

### **Will my taking part be kept confidential?**

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

### **This concludes Part 1.**

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

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## **PART 2**

### **Who is organising and funding the study?**

This study is funded by the WMG at the University of Warwick



### **What will happen if I don't want to carry on being part of the study?**

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

### **What if there is a problem?**

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact the Chief Investigator of the study details overleaf.

### **Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

#### **Director of Delivery Assurance**

Registrar's Office  
University House  
University of Warwick  
Coventry  
CV4 8UW

Complaints@Warwick.ac.uk  
024 7657 4774

### **Will my taking part be kept confidential?**

Yes, written information will not contain your name or any identifiable information. Information supplied to Join Dementia Research including your name, address and phone number will be used by the researcher only for the purposes of arranging to send the questionnaire and will not be passed to any third parties.

Collected data will be kept in a locked filing cabinet, at the International Digital Laboratory at the University of Warwick. Data will be stored on a password protected University computer. All data will be stored for 10 years as per the University of Warwick guidelines. Data storage and handling is in accordance with both the Data Protection Act, and the University of Warwick policy.

### **What will happen to the results of the study?**

The results from this study will be written up and make up part of my PhD thesis. The anonymised data may be discussed with academic supervisors and colleagues within the WMG

The completed study may also form the basis of research papers submitted to academic conferences and journals.

### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Warwick, Biomedical and Scientific Research Ethics Committee (BSREC) **REGO-2016-1796**

### **What if I want more information about the study?**

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information leaflet, please contact:

#### **Chief Investigator**

**Frances Allen**

International Digital Laboratory

University Of Warwick  
Coventry  
CV4 7AL

Email: f.allen@warwick.ac.uk

Tel: 02476 573251

**Academic Supervisors**

**Dr Rebecca Cain**

International Digital Laboratory  
University Of Warwick  
Coventry  
CV4 7AL

Email:

R.Cain.1@warwick.ac.uk

Tel: 02476 575951

**Professor Caroline Meyer**

International Digital Laboratory  
University Of Warwick  
Coventry  
CV4 7AL

Email:

C.Meyer@warwick.ac.uk

Tel: 02476 573585

**Thank you for taking the time to read this  
participant information leaflet.**

## **Consent**

I confirm that have read and understood the Participant Information Leaflet.

I have had the opportunity to consider the information and had any queries answered satisfactorily.

I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason, without my medical, social care, education or legal rights being affected.

1. I agree to take part in the above study. Signed:

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*1.a*

Date:

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## **Screening**

2. Do you have a diagnosis of dementia or are you a carer for a relative or friend of a person with dementia?

I have a diagnosis of dementia and I am completing this alone	<input type="checkbox"/>
I care for a relative or friend with dementia and I am completing this alone	<input type="checkbox"/>
We are a person with dementia and a relative or friend and we are completing the questionnaire together	<input type="checkbox"/>

## **Demographic Information**

If completing this as a pair please answer in relation to the participant with dementia

3. How long ago did you or your family member/friend receive a diagnosis of dementia?

Less than 6 months	<input type="checkbox"/>
6-12 Months	<input type="checkbox"/>
1-3 Years	<input type="checkbox"/>
4-6 Years	<input type="checkbox"/>
7-9 Years	<input type="checkbox"/>
10+ Years	<input type="checkbox"/>
Not sure /don't know	<input type="checkbox"/>

3. b Would you describe yourself as:

White British / White Irish / White Other	<input type="checkbox"/>
Black/African/Caribbean/Black British	<input type="checkbox"/>
Asian/Asian British	<input type="checkbox"/>
Mixed/multiple ethnic groups	<input type="checkbox"/>
Other / please specify	

3. c Please enter your gender

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>
Other, please specify:	

4. What type of dementia have you / your friend or relative been diagnosed with?

Alzheimer's Disease <input type="checkbox"/>	Frontotemporal dementia <input type="checkbox"/>
Vascular Dementia <input type="checkbox"/>	Not sure / don't know <input type="checkbox"/>
Other, please specify:	

5. Please enter your age and if applicable to age of your relative or friend with dementia:

Your age	
The age of the relative or friend with dementia	

6. Which of the following best describes the highest level of education you have completed?

Secondary left before 16	<input type="checkbox"/>
GCSE, CSE, O'level or equivalent	<input type="checkbox"/>
A'level or equivalent	<input type="checkbox"/>
Vocational training e.g. NVQ	<input type="checkbox"/>
Professional qualification	<input type="checkbox"/>
Undergraduate degree	<input type="checkbox"/>
Postgraduate degree	<input type="checkbox"/>

7. Do you live alone?

Yes <input type="checkbox"/>	No <input type="checkbox"/>
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8. Which part of the United Kingdom do you reside?

England	<input type="checkbox"/>
Scotland	<input type="checkbox"/>
Wales	<input type="checkbox"/>
Northern Ireland	<input type="checkbox"/>
Channel Islands	<input type="checkbox"/>
Isle of Man	<input type="checkbox"/>



## **Passive Information**

Sometimes we are given information or advice from others without having looked for or specifically requested it. This is called **passive** information.

9. From which of the following people have you been offered **passive** information regarding dementia and how would you rate the information that they provide?

	1 Very Poor	2 Poor	3 Neither good nor poor	4 Good	5 Very good	Not applicable
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia specialist nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia Advisor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	1 Very Poor	2 Poor	3 Neither good nor poor	4 Good	5 Very good	Not applicable
Friends / Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other carers / people with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Sometimes people notice information about dementia from other sources, even when they are **not** trying to find out about a specific concern. Please indicate if you have ever noticed this type of information from any of the following (Tick all that apply)

Newspapers	<input type="checkbox"/>
Magazines	<input type="checkbox"/>
Radio	<input type="checkbox"/>
Internet	<input type="checkbox"/>
Television	<input type="checkbox"/>
Social Media	<input type="checkbox"/>
Poster	<input type="checkbox"/>

10.a. If you have seen information in this way, have you ever acted on the information that you have seen either by seeking further information or changing something? (Tick all that apply)

Yes by seeking more information	Yes by changing something	No
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10a.i. If Yes, please explain how:

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## **Active information searching**

11. Have you ever **actively** searched for information about dementia, which could include asking questions or setting to find information on a specific topic?

Yes <input type="checkbox"/>	No <input type="checkbox"/>
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**If no please go to question 12.**

11.a From which of the following places have you looked or asked for information about dementia? (Tick all that apply)

Health or social care professional <input type="checkbox"/>	Library <input type="checkbox"/>
Dementia advisor <input type="checkbox"/>	Support group <input type="checkbox"/>
Charitable organisation <input type="checkbox"/>	Telephone helpline <input type="checkbox"/>
Mass media e.g. TV, newspapers <input type="checkbox"/>	Printed information sheet/ booklet <input type="checkbox"/>
Book <input type="checkbox"/>	Internet <input type="checkbox"/>
Social media e.g. facebook <input type="checkbox"/>	Friends / family <input type="checkbox"/>
Other please specify:	

11.b Based on your experiences of seeking information about dementia, how much do you agree or disagree with the following statements?

	1. Strongly agree	2. Agree	3. Neither agree nor disagree	4. Disagree	5. Strongly disagree
It took a lot of effort to get the information I needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt frustrated during the search for information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was concerned about the quality of the information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information was hard to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Please indicate how much you agree/disagree with the following statements:

	1. Strongly agree	2. Agree	3. Neither agree or disagree	4. Disagree	5. Strongly disagree
I feel well informed about issues relating to dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have not received enough advice about dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am unable to take in the amount of information offered to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **Support groups**

13. Do you attend or have you ever attended a support group for carers or people living with dementia?

Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
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**If no, please go to question 13b**

13.a Which groups did/do you attend?

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13.b Would you consider attending a group in the future?

Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
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13.b.i If no please tell us why this is?

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## **The Internet**

14. Do you own or have access to any of the following? (Tick all that apply)

	Own	Have access to
Desktop computer	<input type="checkbox"/>	<input type="checkbox"/>
Laptop computer	<input type="checkbox"/>	<input type="checkbox"/>
Tablet computer	<input type="checkbox"/>	<input type="checkbox"/>
Smartphone	<input type="checkbox"/>	<input type="checkbox"/>
Ordinary mobile phone	<input type="checkbox"/>	<input type="checkbox"/>
Smart TV (a TV with internet access)	<input type="checkbox"/>	<input type="checkbox"/>

15. Do you ever go online to send or receive emails?

Yes <input type="checkbox"/>	No <input type="checkbox"/>
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16. Do you ever go online to use the Internet or World Wide Web?

Yes <input type="checkbox"/>	No <input type="checkbox"/>
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**If no, go to question 17.**



16.a Where do you access the internet? (Tick all that apply)

Home	<input type="checkbox"/>
School	<input type="checkbox"/>
Library	<input type="checkbox"/>
Someone else's home	<input type="checkbox"/>
Internet Café	<input type="checkbox"/>
Mobile e.g smartphone	<input type="checkbox"/>
Other please specify	

16.a.ii In an average week, how often do you use the internet?

Several times a day	<input type="checkbox"/>
Once a day	<input type="checkbox"/>
3-6 times a week	<input type="checkbox"/>
1-2 times a week	<input type="checkbox"/>
Less often than once a week	<input type="checkbox"/>

16.a.iii If you have looked on the internet for information, which of the following types of website have you used when looking for dementia information? (Tick all that apply)

Dementia charity website, e.g. Alzheimer's society	<input type="checkbox"/>
Non-dementia charity website e.g. AgeUK	<input type="checkbox"/>
NHS website e.g. NHS choices	<input type="checkbox"/>
Government website e.g. Department of health	<input type="checkbox"/>
Online Forum, e.g. talking point	<input type="checkbox"/>
Company website, e.g. living aids shops / care homes	<input type="checkbox"/>
Generic website, e.g. Wikipedia	<input type="checkbox"/>
Other, please specify	<input type="checkbox"/>
I have not looked on the internet for information	<input type="checkbox"/>

16.a.iv If you want to find out about an aspect of living with dementia, how likely are you to look for advice on the internet?

Not at all likely <input type="checkbox"/>	Unlikely <input type="checkbox"/>	Somewhat likely <input type="checkbox"/>	Very likely <input type="checkbox"/>	Certain <input type="checkbox"/>
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Why?

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17. If you do not go online to access the Internet or World Wide Web please tell us why? (Tick all that apply)

Not interested	<input type="checkbox"/>
Costs too much	<input type="checkbox"/>
Complicated to use	<input type="checkbox"/>
Do not think it is helpful	<input type="checkbox"/>
Other, please specify	

## **Utility of Information**

18. In general how much do you **trust** information about dementia from the following sources?

	1. Not at all	2. Not really	3. Somewhat	4. Very much	5. Completely	6. Have not used
Health professional e.g. doctor, nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Charitable organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. TV, Newspapers,	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family / friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social care professional e.g social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. books, leaflets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. In general how **understandable** do you find the information provided by the following information sources?

	1. Not at all	2. Not really	3. Some what	4. Very	5. Extremely	6. Have not used
Health professional e.g. doctor, nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. TV, Newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family / friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social care professional e.g. social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. books, leaflets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. In general how easy to **access** do you find the following sources of information?

	1. Very difficult	2. Difficult	3. Neither easy nor difficult	4. Easy	5. Very Easy	6. Have not accessed
Health professional e.g. doctor, nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. TV, Newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family / friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social care professional e.g. social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. books, leaflets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Considering finding information about aspects of living with dementia. Where would you first seek information on the following and what other sources would you use?

### 21.a Medication

	Would look first (Tick one)	Would also look at (Tick all that apply)
Health and social care professional	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>
Friends and family	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. newspapers, TV	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. leaflet, book	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Social media e.g. facebook, twitter	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>
Other.	<input type="checkbox"/>	<input type="checkbox"/>

### 21.b Coping with memory loss

	Would look first (Tick one)	Would also look at (Tick all that apply)
Health and social care professional	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>
Friends and family	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. newspapers, TV	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. leaflet, book	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Social media e.g. facebook, twitter	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>
Other.	<input type="checkbox"/>	<input type="checkbox"/>

**21.c Coping with other symptoms**

	Would look first (Tick one)	Would also look at (Tick all that apply)
Health and social care professional	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>
Friends and family	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. newspapers, TV	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. leaflet, book	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Social media e.g. facebook, twitter	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

**21.d Living aids and equipment**

	Would look first (Tick one)	Would also look at (Tick all that apply)
Health and social care professional	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>
Friends and family	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. newspapers, TV	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. leaflet, book	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Social media e.g. facebook, twitter	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>



### 21.e Emotional support

	Would look first (Tick one)	Would also look at (Tick all that apply)
Health and social care professional	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>
Friends and family	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. newspapers, TV	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. leaflet, book	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Social media e.g. facebook, twitter	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

### 21.f Practical Advice

	Would look first (Tick one)	Would also look at (Tick all that apply)
Health and social care professional	<input type="checkbox"/>	<input type="checkbox"/>
Dementia advisor	<input type="checkbox"/>	<input type="checkbox"/>
Friends and family	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>
Mass media e.g. newspapers, TV	<input type="checkbox"/>	<input type="checkbox"/>
Published material e.g. leaflet, book	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Social media e.g. facebook, twitter	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

22. Overall, how confident are you that you can access appropriate dementia information when you need it?

Completely confident <input type="checkbox"/>	Very confident <input type="checkbox"/>	Somewhat confident <input type="checkbox"/>	Not confident <input type="checkbox"/>	Not at all confident <input type="checkbox"/>
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23. In an ideal world, how would you like to receive information about dementia?

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23.a From your experiences, how close to the ideal do you feel the currently sources of information are?

Not at all close <input type="checkbox"/>	Somewhat distant <input type="checkbox"/>	Not close or distant <input type="checkbox"/>	Somewhat close <input type="checkbox"/>	Extremely close <input type="checkbox"/>
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23.a.i Why?

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24. Which of these factors do you regard as the most important when considering a source of advice about living with dementia, and which is the least important?

	Most Important (Tick one)	Least Important (Tick one)
I can trust the information offered	<input type="checkbox"/>	<input type="checkbox"/>
I can access the information easily	<input type="checkbox"/>	<input type="checkbox"/>
I can receive answers to specific questions	<input type="checkbox"/>	<input type="checkbox"/>
I can search for information	<input type="checkbox"/>	<input type="checkbox"/>
The source is quick to use	<input type="checkbox"/>	<input type="checkbox"/>
Offers information individualised for me	<input type="checkbox"/>	<input type="checkbox"/>
Includes the experiences of others	<input type="checkbox"/>	<input type="checkbox"/>
Offers a broad range of topics	<input type="checkbox"/>	<input type="checkbox"/>
Offers accurate information	<input type="checkbox"/>	<input type="checkbox"/>
Is up to date	<input type="checkbox"/>	<input type="checkbox"/>
Offers information about things I haven't considered	<input type="checkbox"/>	<input type="checkbox"/>

25. Finally, is there anything else about sources of dementia information that you would like us to know?

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## **Survey finished**

Thank you for completing this questionnaire.

If you have any further questions please contact us on the details provided in the Participant information leaflet.

Please now return this questionnaire in the pre-paid envelope provided.

## 12.7 Appendix G: NICE dementia publications and their relevance to home adaptation

NICE Publication	Year published / updated	Clinical guideline or Quality standard	Section	Relevance to home adaptation research
Dementia: Supporting PwD and their carers in health and social care	2006 / 2016	Clinical Guideline	1 Guidance:	
			1.1.10 Environmental design	Health and social care managers who are organising living arrangements should ensure the design of the built environment meets individual needs. Specifically mentions lighting, colour, flooring, AT, signage and access.
			1.2 Integrated health and social care	Health and social care staff should use integration as a framework for assistive technology and telecare.
			1.5 Promoting and maintaining independence of people with dementia	Care plans should address ADLs and maximise independent activity and should always include environmental modifications, AT and advice from OT and/or clinical psychologist.
			2: Notes on scope of guidance	The guideline is relevant to all health and social care staff who care for PwD and their families or carers. This includes those working in hospitals, community, domiciliary care, residential and specialist settings.

NICE Publication	Year published / updated	Clinical guideline or Quality standard	Section	Relevance to home adaptation research
Dementia: Independence and wellbeing	2013	Quality standard	Quality statement 7: Design and adaptation of housing	<p>PwD have housing that meets their needs and adapted to promote independence</p> <p>There should be evidence that staff are trained locally to recognise when home adaptations can help with specific needs.</p>
Dementia: Support in health and social care	2010	Quality standard	<p>Quality statement 3: Written and verbal information</p> <p>Quality statement 4: Assessment and personalised care plan.</p> <p>Quality standard 7: Non-cognitive symptoms and behaviour that challenges</p>	<p>Following diagnosis PwD and their carers receive both written and verbal information about dementia, treatment and local support.</p> <p>All PwD have an assessment and personalised care plan.</p> <p>Interventions that improve behavioural symptoms should be added to care plan.</p> <p>Health and social care professionals working with PwD with non-cognitive symptoms are given a comprehensive assessment which must include physical environment factors.</p>

## 12.8 Appendix H: Practitioner study questionnaire including vignette scenarios and derivations

Section	Question Number	Question	Question Type	Research Question Answered
Consent	1	Do you give consent to take part in this study?	Yes/No	N/A
Screening	2	Do you provide face to face advice to PwD who still live at home and /or their carers as part of your role?	Yes/No	N/A
Demographic Information	3	What age group are you in?	MCSA	N/A
	4	How would you describe your role with PwD and their carers?	MCSA	RQ2
	4.b	Which of the following best describes your area of work?	MCSA	RQ2
	4.c	Briefly describe the main purpose of your service/role	Open	RQ2
	4.d	How long have you held a role where you provide advice to PwD and their carers?	MCSA	N/A
Practitioner Learning	5	Have you ever seen or heard professional information about modifying the physical environment to assist living with dementia?	Yes/No	RQ1
	5.a	Where have you seen/heard professional information about modifying the physical environment in dementia?	MCMA	RQ1
	5.b	Having seen or heard this information did this lead you to specifically look for more information?	Yes/No	RQ1
	5.c	Having seen or heard this information did this lead you to change your practice in any way?	Yes/No	RQ1
	5.c.i	Please could you specify how your practice changed?	Open	RQ1
	6	Have you ever specifically searched for information about how design and the physical environment can affect people with dementia?	Yes/No	RQ1



Section	Question Number	Question	Question Type	Research Question Answered
	6.a	Where have you actively searched for information regarding the physical environment impacts on living with dementia?	MCMA	RQ1
	6.b	What led you to search for information about adapting the home environment in dementia?	MCMA	RQ1
	7	Which of the following statements best describes your level of knowledge regarding home adaptation for dementia?	MCSA	RQ1
	7.a	Which if the following statements best describes how you feel about your knowledge regarding home adaptation?	MCSA	RQ1
Information Provision	8	On which of the following aspects do you offer advice or information to PwD and their carers?	MCMA	RQ2,RQ3
	9	Do you ever give out general advice regarding how making changes to the home environment can assist with living at home with dementia?	Yes/No	RQ2
	9.a	What form does this take?	MCMA	RQ2,RQ3
	9.b	Do you feel that the provision of advice about the home environment for PwD falls within your role?	Yes/No	RQ2
	9.c	What initiates the provision of this advice / information?	MCMA	RQ2
Recommendations and Equipment	10	Do you ever make recommendations about specific adaptations to the homes of individuals with dementia or their carers?	Yes/No	RQ2,RQ3
	10.a	Following a recommendation to make a specific adaptation, how likely is it that an individual with dementia or their carer will carry out the recommended changes?	Likert	RQ3
	10.b	Does your service provide any equipment for PwD living at home?	Yes/No	RQ2
	10.b.i	Which types of equipment does your service provide?	MCMA	RQ3

Section	Question Number	Question	Question Type	Research Question Answered
	10.c	Generally, how do you think PwD and their carers feel about making changes to their homes?	Open	
	10.c.i	Why?	Open	
Vignettes	11, 13, 15, 17, 19	Would you offer any advice or information regarding modification of the home environment or use of equipment in this situation?	Yes/No	RQ2,RQ3
	11.a, 13.a, 13.a, 15.a, 17.a, 19.a,	Please outline which information / advice you would offer specifically regarding modification of the environment and use of equipment. Please also briefly describe and any further questions / assessment you may complete	Open	RQ2,RQ3
	12,14,16,18,20	Would you signpost / refer to any other services?	Yes/No	RQ3
	12.a, 14.a, 16.a, 18.a, 20.a	Which services would you signpost to?	Open	RQ3
Final comments	21.	Is there anything you would like to add about your knowledge of and how you provide advice and information about adapting the home for dementia?	Open	N/A

MCSA= Multiple choice single answer

MCMA= Multiple choice multiple answer



# **INCREASING THE UPTAKE OF HOME ADAPTATION FOR DEMENTIA.**



A findings leaflet by

Fran Allen

## **Increasing the uptake of home adaptation for dementia.**

### **Background**

Dementia is an umbrella term for a range of symptoms caused by degeneration of areas of the brain. This damage becomes progressively more pronounced and causes cognitive impairment, reduced communication, reasoning and loss of functional capacity.

Home adaptation has been shown to be beneficial in the homes of people with dementia by mitigating dementia symptoms and behaviours. These concepts include changing colour, lighting, sound, temperature and the use of living aids. Advice detailing how home adaptation can be used by people with dementia and those with whom they live is available from a number of different sources and formats.

Although two thirds of people with dementia live in the community there remains a lack of understanding how people adapt their homes following a diagnosis of dementia and what the barriers to this are.

### **About the study**

The project consisted of three studies:

1. To explore the use of home adaptation by people with dementia and those with whom they live and how they feel about making changes to their homes.
2. The second study investigated how comprehensible and accessible people find different information sources and how individuals would prefer to receive information about dementia.
3. To identify what home adaptation information is provided by health, social care and charity practitioners and how professionals feel about their own level of home adaptation for dementia knowledge.

The experiences of people with dementia, close family members and friends along with health and social care practitioners were gathered. In total ten couples consisting of a participant with dementia and someone with whom they lived, were interviewed in their own homes, 214 people with close family members or friends completed a survey about information and 58 practitioners completed a vignette questionnaire about their home adaptation knowledge. The data and information provided by participants was analysed and used to produce recommendations for improved implementation of evidence based home adaptations.

## Summary of Key findings

The recommendations are of use to three separate groups; people with dementia and their carers, practitioners and service leads and finally designers and industry.

### **Recommendations for people with dementia and their carers**

- **Proactive home adaptation can provide long term support.**

Evidence suggests that home adaptation can prevent the onset of crisis, reduce feelings of carer burden, and promote independence for people with dementia. Health or social care crisis can be avoided or delayed by introducing home adaptation proactively, for example, fitting hand rails, improved task lighting and removing over stimulating decor.

- **Consider how changes and new technology will affect dementia symptoms.**

When making changes to the home such as redecorating, purchasing new appliances and technology, it is important that families living with dementia realise that these changes can alter how a person with dementia is able to function, both positively and negatively. For example new technology may be unfamiliar and mean that the individual with dementia can no longer use it.

- **Use a broad range of sources to feel well-informed about dementia.**

Using a mix of different information sources, for example asking questions from health professionals, conducting internet searches and speaking to family and friends, helps individuals to feel well informed about dementia. This means that information from one source can then support or explain information from somewhere else information sources and assists in an individual's ability to check the quality of information, whilst providing an increased level of accessibility.

## **Recommendations for practitioners and service leads.**

- **Earlier provision of home adaptation information**

Include information about home adaptation and how this can positively influence living well with dementia in post-diagnosis passive information. This could include, inclusion in booklets, signposting to online information and patient information sheets. Passive information is a positive step towards encouraging active information seeking and acceptance.

- **Benefits of early adaptation.**

Early home adaptation information would also benefit from the subtle inclusion of information which makes it clear that due to the progressive nature of the condition, home adaptation and equipment is better considered early in the disease process when it can be adapted to.

- **Improved training**

Practitioners who work with people with dementia, particularly those who have contact prior to periods of crisis, for example: dementia advisors who work for dementia charities, and GPs require specific training in how the home environment can help support those with dementia. Providing training for practitioners would help to provide consistent support and information.

- **Service change to focus on pre-crisis intervention.**

Secondary to the above. Improving access to Occupational Therapists following a dementia diagnosis would assist with the receipt of passive information. Occupational therapists are also able to assess the home and make recommendations. However currently their skills are often not accessible until a crisis point has already been reached.

- **Providing free of charge, evidence based information.**

There is a need for a comprehensive, free information resource regarding home adaptation for dementia. The currently available information sources are very selective in their provision of evidence based recommendations, books are available at a cost or information is produced from companies who are selling equipment which makes their advice liable to bias. All of these aspects limit those who are able to access the advice.

Internet use is widespread amongst those who care for someone with dementia and a web based repository for the placement of home adaptation information would be accessible as an adjunct to signposting from frontline healthcare professionals. A single, comprehensive resource would be more responsive to new evidence, techniques or equipment which becomes available.

- **Provision of individualised information.**

A one size fits all method of information provision is not effective in dementia. Creating building blocks of information for dementia, including home adaptation means that information can be personalised and given at a pace and a time that reflects both the stage of dementia, their ability to take on health knowledge and the level of acceptance of the condition currently experienced by patients, service users and consumers.



## **Recommendations for designers and industry.**

- **Mainstream dementia information and design.**

There are current advances being made in the reduction of stigma in dementia, created by increased public awareness and campaigns such as 'Dementia Friends'. As dementia knowledge reaches the public domain, there is an opportunity for mainstream designers and high street retailers to create products and services with dementia in mind. This would create a cyclical process where improved design itself helps to lower stigma and encourages further design innovation.

- **Retail opportunities lie within dementia design.**

As dementia diagnosis rates improve and occur earlier in the disease process through improved awareness, there is a growing market for well-designed, practical and aesthetic living aids and equipment which offer an alternative to the utilitarian equipment which is offered through health and social services. This impacted on the ageing of the 'baby boomer' generation (those born between 1946-1964), who are now aged between 50 and 70 and have differing expectations from the generations that came before.

## **Further Information**

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